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## ABSTRACT

This participant's manual presents materials for a national conference (May 2002) on youth leadership development within organizations of disabled individuals. Introductory material includes the conference agenda, information about the trainers, and information about the sponsoring organizations, the Independent Living Research Utilization Program and the National Council on Independent Living, which have developed the Independent Living (IL) Net. Following a list of learning objectives, two sections provide an introduction to collaboration and disability culture. Section 3 considers the emerging disability policy framework with a reprint of an article by Robert Silverstein entitled: "Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy." Section 4 provides a resource manual entitled: "How To Conduct a California Model Youth Leadership Forum for Students with Disabilities. Section 5 explains the Yield the Power Project, a federally funded demonstration grant intended to increase the participation of youth with disabilities in mainstream workforce development activities. This section also includes a guide to running a youth focus group. (DB)

IL NET Presents...

ED 468 364

# Nothing About Youth Without Youth

May 16-17, 2002

Salt Lake City, UT

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Expanding the Power of the Independent Living Movement

## **IL NET**

an ILRU/NCIL National Training and Technical Assistance Project

*Expanding the Power of the Independent Living Movement*

# **NOTHING ABOUT YOUTH WITHOUT YOUTH**

A National Conference

## **Participant's Manual**

**May 16-17, 2002**

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# Nothing About Youth Without Youth

Salt Lake City, UT

May 16-17, 2002

## Participant's Manual

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# **Nothing About Youth Without Youth**

## **Agenda**

### **THURSDAY, MAY 16**

8:30	Continental Breakfast
9:00 – 9:05	Welcome and Introductions
9:05 – 9:45	Opening Dialogue: A Framework for Leadership Development Facilitated by Curtis, Sarah and Marissa
9:45 – 10:30	A Historical Context: Where Have We Been? Curtis, Sarah and Marissa
10:30-10:45	Break
10:45-12:00	Where Are We Going? Curtis, Sarah and Marissa
12:00- 1:30	Lunch On Your Own
1:30 – 2:15	The Barnnga Exercise: Understanding Youth Culture Facilitated by Sarah and Dellon
2:15 – 2:45	Incorporating Independent Living Philosophy into Youth Programs Curtis, Sarah and Marissa
2:45 – 3:00	Break
3:00 – 4:45	Brag and Steal Session and Dialogue
4:45 – 5:00	Summary of Today and Overview of Tomorrow's Agenda Marissa

## **FRIDAY MAY 17**

8:30	Continental Breakfast
9:00 – 10:30	Tools and Strategies for Creating and Running Youth Programs Sarah, Dellon, Curtis, and Marissa
10:30-10:45	Break
10:45-12:15	Getting Started Sarah, Dellon, Curtis and Marissa
12:15- 1:45	Lunch on Your Own
1:45 – 2:45	Shaping Policy That Furthers Leadership Development Marissa, Sarah, Dellon, and Curtis
2:45 – 3:00	“Rap”-up Dellon

## About the Trainers

**Marissa Johnson**, 25, is currently the Co-Chair of the National Youth Leadership Network, an organization dedicated to advancing the next generation of disability leaders and the host of the National Leadership Conference for Youth with Disabilities. Marissa is also on committees for the National Center on Secondary Education and Transition, the National Collaborative on Workforce and Disability/Youth and is on the Youth Advisory Council for the Presidential Task Force on Employment of Adults with Disabilities. In addition to her national involvement, Marissa is a Disability Rights Advocate establishing youth programs at The Whole Person, a CIL in Kansas City, MO.

**Dellon Lewis**, a 20-year old man with a physical disability, is the Youth Leader/Organizer for the YIELD THE POWER Project at Access Living of Metropolitan Chicago. Dellon is a National Honors Society graduate from Jesse Spalding High School located in Chicago. He was selected to participate in the citywide high school mock trial at the Richard M. Daley center in Chicago. Dellon was a participant in a nationwide organization of wheelchair basketball and other extra curricular activities while a student at Spalding High. In 1995, he won first place in the national competition of poetry of Martin Luther King, Jr. and his entry was placed in the Martin Luther King, Jr. Library in Montgomery, Alabama. He received an award for outstanding advocacy and mentorship at Pyramid Career Institute in 2001, and graduated that year for computer driven customer service.

**Curtis Richards** is the former Deputy Assistant Secretary for the Office of Special Education and Rehabilitative Services under Judy Heumann where he was involved in helping shape both the funding and program of the first national Youth Leadership Conference. Prior to this while working for the California Department of Rehabilitation he helped secure the funding to launch the first Youth Leadership Forum in the country. He served as a camp counselor and mentor to several young people with disabilities (including Sarah Triano) at that Forum. Curtis also served as co-chair of the presidential Task Force's Subcommittee on Youth, in which he lead efforts to do cross agency policy work to help address employment issues for young adults with disabilities, including leadership development. Curtis now has his own consulting firm and is a key consultant with the National Collaborative on Workforce and Disability/Youth, a Department of Labor funded technical assistance center.



**Sarah Triano** is a 27 year-old young woman with a non-apparent disability, and one of the leading youth activists in the country. She is a co-founding member of the UIC Disabled Students Union and the National Disabled Students Union (NDSU), and also serves on the Young Activists' Task Force of the American Association of People with Disabilities. Sarah is currently a graduate student at the University of Illinois Chicago pursuing her Doctoral degree in Disability Studies, while also working as the Youth/Education Team Leader and YIELD THE POWER Project Director at Access Living of Metropolitan Chicago. She was one of the original delegates to the first annual California Youth Leadership Forum for High School Students with Disabilities in 1992. She volunteered as a counselor at this Forum from 1993-1998, and was actively involved with the Office of Disability Employment Policy (formerly known as the President's Committee on Employment of People with Disabilities) in the replication of this model youth leadership forum throughout the United States. After participating in the 1998 National Council on Disability's Second Annual Youth Leadership Development Conference in Washington, DC., Sarah contracted with NCD to produce a policy report on the issues facing minority-group members with disabilities in the U.S. entitled, "Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation," which was released on July 26, 1999.

## Trainers

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## **ABOUT ILRU**

The Independent Living Research Utilization (ILRU) Program was established in 1977 to serve as a national center for information, training, research, and technical assistance for independent living. In the mid-1980's, it began conducting management training programs for executive directors and middle managers of independent living centers in the U.S.

ILRU has developed an extensive set of resource materials on various aspects of independent living, including a comprehensive directory of programs providing independent living services in the U.S. and Canada.

ILRU is a program of TIRR, a nationally recognized, free-standing rehabilitation facility for persons with physical disabilities. TIRR is part of TIRR Systems, a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.

## **ABOUT NCIL**

Founded in 1982, the National Council on Independent Living is a membership organization representing independent living centers and individuals with disabilities. NCIL has been instrumental in efforts to standardize requirements for consumer control in management and delivery of services provided through federally-funded independent living centers.

Until 1992, NCIL's efforts to foster consumer control and direction in independent living services through changes in federal legislation and regulations were coordinated through an extensive network and involvement of volunteers from independent living centers and other organizations around the country. Since 1992, NCIL has had a national office in Arlington, Virginia, just minutes by subway or car from the major centers of government in Washington, D.C. While NCIL continues to rely on the commitment and dedication of volunteers from around the country, the establishment of a national office with staff and other resources has strengthened its capacity to serve as the voice for independent living in matters of critical importance in eliminating discrimination and unequal treatment based on disability.

Today, NCIL is a strong voice for independent living in our nation's capital. With your participation, NCIL can deliver the message of independent living to even more people who are charged with the important responsibility of making laws and creating programs designed to assure equal rights for all.

## **ABOUT THE IL NET**

This training program is sponsored by the IL NET, a collaborative project of the Independent Living Research Utilization (ILRU) of Houston and the National Council on Independent Living (NCIL).

The IL NET is a national training and technical assistance project working to strengthen the independent living movement by supporting Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs).

IL NET activities include workshops, national teleconferences, technical assistance, on-line information, training materials, fact sheets, and other resource materials on operating, managing, and evaluating centers and SILCs.

The mission of the IL NET is to assist in building strong and effective CILs and SILCs which are led and staffed by people who practice the independent living philosophy.

The IL NET operates with these objectives:

- Assist CILs and SILCs in managing effective organizations by providing a continuum of information, training, and technical assistance.
- Assist CILs and SILCs to become strong community advocates/change agents by providing a continuum of information, training, and technical assistance.
- Assist CILs and SILCs to develop strong, consumer-responsive services by providing a continuum of information, training, and technical assistance.

# **NOTHING ABOUT YOUTH WITHOUT YOUTH**

## **Learning Objectives**

Participants will:

- 1) Gain an historical perspective and national context for youth leadership development;
- 2) Identify how to incorporate independent living philosophy into youth programs;
- 3) Learn the secrets of success of model youth leadership programs;
- 4) Learn how to integrate the best from mainstream youth leadership programs with those designed specifically for youth with disabilities;
- 5) Acquire tools and strategies to create and operate local and/or statewide programs.

It is time for a new generation of leadership,  
to cope with new problems and new opportunities.  
For there is a new world to be won.

--President John F. Kennedy

# Collaboration



# Context for Collaboration

In a tumultuous swiftly changing environment, in a world of multiple colliding systems, the hierarchial position of leaders within their own system is of limited value, because some of the most critically important tasks require lateral leadership – cross boundry leadership – involving groups over whom they have no control

**Source: On Leadership, John Gardner**

# Elements of Reform

- Collaborative Decision Making
- Public Engagement
- Parent Consumer and Neighborhood Participation
- Accountability for Results

# **Stages of Collaboration**

- Getting Together
- Building Trust and Ownership
- Strategic Planning
- Taking Action
- Deepening and Broadening the Work

## Why NCWD/ Youth is needed

- \*Youth with disabilities, especially those with significant disabilities, experience particularly poor education and employment outcomes.
- \*One third of students with disabilities do not finish high school.
- \* Only one third of young people with disabilities who need job training receive it.
- \* Only a quarter of young people who need life skills training, tutoring, interpreting or personal counseling receive these services.
- \* More than half of all young people with emotional disturbances are arrested at least once within three to five years of exiting school.
- \*Young people with disabilities have significantly lower rates of participation in post secondary education.
- \* Only 26 percent of working age adults with disabilities have a job or their own business.

## Collaborative Members

- Center for Workforce Development at the Institute for Educational Leadership ([www.iel.org](http://www.iel.org))
- Disability Studies & Services Center at the Academy for Educational Development ([www.aed.org/ctrdssc](http://www.aed.org/ctrdssc))
- National Center on Secondary Education & Transition at the University of Minnesota ([www.ici.umn.edu/ncset](http://www.ici.umn.edu/ncset))
- TransCen, Inc. ([www.transcen.org](http://www.transcen.org))
- InfoUse ([www.infouse.com](http://www.infouse.com))
- Goodwill Industries International, Inc. ([www.goodwill.org](http://www.goodwill.org))
- Learn, Earn & Work Project at the National Conference of State Legislatures ([www.ncsl.org/program/s/em\\_play](http://www.ncsl.org/program/s/em_play))
- Center for Workforce Preparation at the U.S. Chamber of Commerce ([www.uschamber.com/CWP](http://www.uschamber.com/CWP))
- National Association of Workforce Boards ([www.nawb.org](http://www.nawb.org))
- National Youth Employment Coalition ([www.nyec.org](http://www.nyec.org))

## National Collaborative on Workforce and Disability

### NCWD

For Youth

## National Collaborative on Workforce and Disability

National Collaborative on  
Workforce and Disability for Youth  
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[www.ncwd-youth.info](http://www.ncwd-youth.info)

# Introducing NCWD/ Youth

In late 2001, the Office of Disability Employment Policy (ODEP) in the U.S. Department of Labor funded two national technical assistance centers designed to **assist the workforce development community to overcome the issues affecting the employment of people with disabilities**. One of these centers focuses its activities on adults with disabilities and the other on youth with disabilities.

The **National Collaborative on Workforce and Disability for Youth (NCWD/ Youth)** is composed of partners with expertise in disability, education, employment, and workforce development issues. The Collaborative is charged with assisting state and local workforce development systems to integrate youth with disabilities into their service strategies. The Collaborative is housed at the Institute for Educational Leadership in Washington, DC.

The Collaborative strives to ensure that youth with disabilities are provided full access to high quality services in integrated settings, in order to maximize their opportunities for employment and independent living.

## Products and Services

Over its five-year life, the Collaborative will offer a range of services to state and local workforce investment boards, youth councils, other workforce system youth programs, and to ODEP grantees. Products and services will include:

- *A fully-accessible, content-rich website; A repository of materials generated by the ODEP grantees;*
- *A research based framework for evaluating state and local "best practices;"*
- *Specialized support to the Department of Labor's High School/High Tech and Innovative Demonstration grantees;*
- *Publications tailored to the needs and concerns of the various workforce development stakeholder groups;*
- *Capacity-building training materials for use by state and local workforce development organizations;*
- *An information and resource center accessible to the public and to the workforce development system; and, Development of materials and specialized training designed to improve the capacity of frontline service providers.*

ODEP also funded a series of demonstration grants designed to test and build a set of "promising practices models." Seven local organizations were awarded Innovative Demonstration Grants for Youth with Disabilities for testing various models of youth empowerment and employment development. The Department of Labor also invested in realigning a number of existing High School/High Tech programs with the workforce investment system and starting a handful of new High School/High Tech programs around the country. **The High School/High Tech Program** provides opportunities for students with disabilities to explore careers in science, mathematics and technology. The Program is one of several initiatives of the Office of Disability Employment Policy (ODEP).

**For more in formation call or visit our Web sites:**

**National Collaborative on Workforce and Disability for Youth**

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877-871- 0744-Toll-free for general

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[www.infouse.com/highschool-hightech](http://www.infouse.com/highschool-hightech)

877-871-4748---Toll-free for information on High School High Tech sites

# Disability Culture

# In Search of Disability Culture

By Miriam Braunstein

(a discussion of issues of importance to the philosophy of the Youth Leadership Forum)

Although disabled since age 8, I was almost 19 years old before I had any inkling that there was something people call disability culture.

I first heard about it three years ago from a friend living in Berkeley, Calif., who happened to be picking up a few hours working for Hale Zukas, a founder of the Berkeley Center for Independent Living. Zukas had also helped build the World Institute on Disability alongside its founders, Judith Heumann, Joan Leon and the late Ed Roberts. Then, of course, those names meant nothing to me.

"There's a magazine with angry letters," my friend said, referring, I believe, to *The Disability Rag*. "And there's one with the quadriplegic *Playboy* model. They have stories, ads, stuff like that."

Well, who would believe a story like that? As proof, he sent copies of these things, along with ADAPT sticker cutouts and WID literature. I was mesmerized. Nineteen years as a Jew, with all the history it entails, had not prepared me for anything like this. At first, even the idea of catheter ads was liberating. I had no idea that disability was discussed outside the hospital wards. I didn't know that disabled people talked to one another, much less organized.

As intrigued as I was, my able-bodied parents were wary. As my interest grew, they moved from nervous to terrified and finally to combative.

"What," my mother asked, "is with this crippled thing? Why are you reading this stuff?"

"Well, I like to read about other disabled people," I said, or something near. "I like to hear what they think." They think like me, is what I was thinking, but not saying.

"Well, you have nothing in common with them." said my father, and that was all they wanted to hear of it. Culture was important things, they said, like your religion. A disease shouldn't define you.

To their minds, as to the minds of any number of nondisabled people operating under old notions about the nature of disability, I was a nice Jewish girl who was sick. And even if it wasn't my fault, I certainly wasn't supposed to run around flaunting it, for heaven's sake. A little decorum and embarrassment, please!

In other words, my disability was a circumstance, not a part of who I was.

### ***A Skewed History***

I was getting my first taste of sharing a common culture with those I increasingly felt were my people, and it was intoxicating. If this was disability culture, I had to find my own place in it, regardless of what any number of able-bodied people thought.

That is not as simple as it seems. It is easy to find signs of disability culture; I had the magazines, a bit of history and a feeling of kinship with the disabled community. I had *When Billy Broke His Head... and Other Tales of Wonder*, a couple of bios of famous gimps, a threatening bumper sticker and a real desire to find out who I was.

What I didn't have was a solid feeling of what, exactly, disability culture is or why it should be so upsetting to the able-bodied people in my world. And that is what I began looking for.

Steven Brown, a co-founder of the Institute on Disability culture in Las Cruces, N.M., has spent a good deal of time considering the elusive combination of disability and culture. To Brown, it is the communal experience of oppression and resilience that generates the art, music and literature of disability culture.

"Most importantly," Brown says, "we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity."



It is, however, an identity that can be amazingly hard to come by. Unlike other established cultures, we have precious little family tradition; with the exception of some hereditary disabilities, disabled children are not usually born to disabled parents. Give Brown's model—which places the history of oppression that disabled people share firmly at its epicenter—this lack of intergenerational contact is a decided disadvantage.

"What we don't have is parents with disabilities teaching kids with disabilities," he says. "What we do have is people of an older generation teaching people of a younger generation."

The triumphs of modern medicine have gone a long way toward providing second and third generations. In the days when spinal cord injury was, at best, something you could survive but not live with, when muscular dystrophy and spina bifida were fatal and most other people with disabilities were kept in back bedrooms or in institutions, older disabled role models were hard to come by. Only after people with disabilities were let out of the house with Section 504, IDEA and, later, the ADA, and only after medicine advanced enough to keep us alive if not kicking, was there any chance of an oral history being discovered. It exists, says Brown, but it isn't easily accessible.

"We didn't think we had a history," he says. "Well, we have one, but nobody thought it was worth telling."

If the key to disability culture lies in our history, as Brown suggests, then a whole new problem arises; namely, how to access that history. A sprinkling of books written in the past few years—*No Pity* and *Enforcing Normalcy*, for example—focus on disability history and several more at least touch on it, but before the early 1980s, very little was written on disability that wasn't clinical. Even less, with a few notable exceptions, was written by disabled people.

That is the biggest problem, says writer and performance artist Cheryl Marie Wade, who lives in Berkeley. If disability history is recorded by nondisabled people, it isn't really a part of disability culture.

"Disability culture!" says Wade, "is disabled people talking about ourselves." And it is able-bodied people, she says, who apportion money for the disabled artistic community-

thus negating the point of disability culture.

"A lot of the programs were started by well-meaning able-bodied people," Wade says. "But the community outgrew the organizations, and the organizations don't reflect that. The paid positions are held by able-bodied people. They set the tone. They set the agenda."

As long as that is the case, she says, disability culture is a footnote to mainstream culture, "a subculture."

Wade says her work expresses, to the best of her ability, what it is to be disabled. She will scream, yell, wave her bent hands in people's faces. That, she says, is one component of disability culture--to bring the existence of a whole group of people with an entirely separate agenda and lifestyle to the attention of the mainstream community. This is the part of disability integration that cannot be legislated.

"Just because we have ramps doesn't mean people look at us as human beings," Wade says. "The point is to say, 'Hey you, we're not just like you, but so what?'"

**"We didn't think we had a history. Well, we have one, but nobody thought it was worth telling."**

**-Steve Brown**

Like Brown, Wade points to pride as a definitive part of culture. It was not until she threw the shawl that she used to hide her hands off her lap and out of her life that Wade was able to become an artist and confront society's view of the disabled.

### ***A Schizophrenic Line***

Paradoxically, disability culture is held to be both a means to insulate ourselves from the larger society and a means to integrate ourselves. Again, says Brown, it comes down to confidence- and pride. If the disabled community can band together in its culture, it can force its way into the collective consciousness of mainstream culture.

"It's the opposite of anti-mainstream," Brown says. "It's not possible for people with disabilities to truly integrate until we are recognized as having pride in who we are as disabled people."

"We walk an almost schizophrenic line," agrees Tom Kemp, CEO of Very Special Arts, an organization based in Washington, D.C., that funds disabled artists worldwide. "We talk inclusion, and then we talk disability pride."

Like Brown, Kemp says the two goals can coexist. Pride, he says, is making claims for our rights based on self-worth, and disability culture is expression of the ways in which we value ourselves and our contributions.

"A whole lot of people don't know how the arts can express what joyous lives we can have," Kemp says, and the ignorance includes disabled people.

There is no way of knowing how few or how many people actually understand disability pride, or really experience it. Most disabled college-age people were born after Section 504, and were still in their mid-teens when the ADA was passed. In spite of all the legislation, disability culture, history, pride and activism are still, for many people, an accidental find. They are spread primarily through community word-of-mouth, which doesn't work well in an isolated and fragmented population. Access to disability culture must be increased, Kemp says, if young people are to continue to help it to develop.

**"We walk an almost schizophrenic line. We talk inclusion, and then we talk disability pride."**

**-John Kemp**

"They need to know who their heroes are," he says. "It's a funny thing, because I was always told I had to compete in the 'real world.' Now I know that disability is a part of who I am, and young people need to know that, too." This realization, Kemp says, makes it possible for disabled people to compete to the best of their abilities without denying their disabilities.

Linda Carpenter, 27, who has a congenital disability, says that during her childhood, disabled role models were simply not available. Carpenter, though, says the lack of available "heroes" in the disabled world did not leave her isolated or without resources.

"It made me more mainstreamed, and I'm glad I was mainstreamed," she says. "I didn't really think it was a bad thing to be like everybody else." Carpenter learned that she could relate normally to able-bodied people. "I broke a lot of braces jumping off things

like the other kids," she says.

In her 20s, and for reasons she doesn't yet understand, Carpenter initiated more relationships among her disabled peers. "I found some people I wanted to be friendly with, I suppose," she says. The need for guidance and camaraderie she responded to extends from people growing up with disabilities to people whose disabilities are acquired later in life.

### ***Subcultures, Multicultures***

When Detroit writer Clark Iverson developed epilepsy 16 years ago at age 20, he had no idea, he says, of the existence of disability culture.

"I grew up thinking one way, and I was forcibly made to think another way," Iverson says. "I've become aware [of disability culture] gradually, over the past 10 years or so."

Iverson's epilepsy is normally unnoticeable, so his involvement has come in spite of nondisabled friends who are puzzled by his attraction to disability issues. His primary commitment has been political, he says; most of disability culture is something that "falls under the heading of one of the things in life I haven't had time to pursue." He doubts that he'll become actively involved in other aspects of disability culture, a concept that to him is self-limiting anyway; he does not think such a large and diverse group can bond effectively.

Congenital amputee Michael Paul of Warren, Mich., takes Iverson's doubt one step further; he says disability culture, while a trendy concept, has had little impact on his life. He doesn't believe any sort of true disability culture can exist at all.

"The fact that there are nondisabled people in the world makes it impossible." Paul says. "We're not living on a gimp desert island. A leper colony is the closest we can come to disability culture--disability subculture, maybe."

Instead of pursuing disability culture, Paul says, disabled people should simply accept themselves and work on making mainstream culture accept our differences and appreciate our similarities. This concept is not necessarily at odds with disability culture, say Brown.

"Everybody is a part of different cultures," he says. "It's one more way to define yourself."

There is no consensus that I have found on what will happen to disability culture. Nobody can predict the development of a trend in its embryonic stages and, for now, that is precisely where disability culture is. It remains an inexact and distinctly flawed concept; hard to define, hard to find, hard to spread. Within it are any number of branches; it is, most say, about pride, and we can demonstrate our pride in many different ways.

But you don't have to define disability culture to notice it, to understand it or to crave it. I suppose the worst fear of my Yiddeshe mama has been fulfilled; I have found another heritage to identify with. Just as surely as I want to visit Jerusalem, I want to make a pilgrimage to Berkeley-to see the first stirrings of the independent living movement. I apply myself to the history of ADAPT the way my grandfathers read the Talmud.

But as I bring disability culture into the stew of unlikely things that produced who I am, it becomes less urgent and all-encompassing. Probably, it will eventually settle in next to all the other words I use to define myself: Jewish, Italian, female, brunette, whatever. It will become another part of my personality, integral but not overwhelming.

I went to my parents' house a while back to visit my mother, newly home from a jaunt to Israel. She was on a heritage kick, humming the Israeli anthem, brandishing a copy of the *Jerusalem Post* and handing out Hebrew name necklaces left and right.

"Here," she said, tossing one over my head. "So you don't forget who you are."  
I put it on; it was pretty and would help any Hebrew-speakers who wonder who I am.  
"You know, ma," I said, "I am still Jewish."

She waved that off, and leaned down to me. "Just remember," she murmured, "where you come from."

Because it isn't until you know where you're from that you can figure out where you're going-as a disabled person or as anything else.

# **Emerging Disability Policy Framework**

# IOWA LAW REVIEW

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## **Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy**

Robert Silverstein

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## APPENDIX 1

# An Overview of the Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy

Robert Silverstein\*

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## INTRODUCTION

Society has historically imposed attitudinal and institutional barriers that subject persons with disabilities to lives of unjust dependency, segregation, isolation, and exclusion. Attitudinal barriers are characterized by beliefs and sentiments held by nondisabled persons about persons with disabilities. Institutional barriers include policies, practices, and procedures adopted by entities such as employers, businesses, and public agencies.<sup>1</sup>

Sometimes, these attitudinal and institutional barriers are the result of deep-seated prejudice.<sup>2</sup> At times, these barriers result from decisions to follow the "old paradigm" of considering people with disabilities as "defective" and in need of "fixing."<sup>3</sup> At other times, these barriers are the result of thoughtlessness, indifference, or lack of understanding.<sup>4</sup> It is often difficult, if not impossible, to ascertain precisely why the barriers exist.

In response to challenges by persons with disabilities, their families, and other advocates, our nation's policymakers have slowly begun to react over the past quarter of a century. They have begun to recognize the debilitating effects of these barriers on persons with disabilities and have rejected the "old paradigm."

A "new paradigm" of disability has emerged that considers disability as a natural and normal part of the human experience. Rather than focusing on "fixing" the individual, the "new paradigm" focuses on taking effective and meaningful actions to "fix" or modify the natural, constructed, cultural, and social environment. In other words, the focus of the "new paradigm" is on eliminating the attitudinal and institutional barriers that preclude persons with disabilities from fully participating in society's mainstream.

Aspects of the "new paradigm" were included in public policies enacted in the early 1970s.<sup>5</sup> Between the 1970s and 1990, lawmakers further defined and society further accepted the "new paradigm."<sup>6</sup> In 1990, the "new paradigm" was explicitly articulated in the landmark Americans with Disabilities Act (ADA)<sup>7</sup> and further refined in subsequent legislation.<sup>8</sup>

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1. See Americans with Disabilities Act of 1990 § 2(a), 42 U.S.C. § 12101(a) (1994) (listing congressional findings regarding Americans with disabilities); see also S. REP. NO. 101-116, at 5-20 (1989). Former Senator Lowell Weicker testified before Congress "that people with disabilities spend a lifetime 'overcoming not what God wrought but what man imposed by custom and law.'" *Id.* at 11.

2. S. REP. NO. 101-116, at 5-7.

3. See National Institute on Disability and Rehabilitation Research, 64 Fed. Reg. 68,576 (1999) (providing notice for the final long-range plan for fiscal years 1999-2003 and explaining that the new paradigm of disability is an expectation for the future).

4. S. REP. NO. 101-116, at 5-7.

5. Rehabilitation Act of 1973, 29 U.S.C. ch. 16 (1994); See Education for All Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 773 (adding Part B to the Individuals with Disabilities Education Act, 20 U.S.C. ch. 33 (1994)).

6. Fair Housing Amendments Act of 1988, Pub. L. No. 100-430, 102 Stat. 1619; Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987, Pub. L. No. 100-146, 101 Stat. 840; Rehabilitation Act Amendments of 1986, Pub. L. No. 99-506, 100 Stat. 1807; Education of the Handicapped Act Amendments of 1986, Pub. L. No. 99-457, 100 Stat. 1145; Air Carrier Access Act of 1986, Pub. L. No. 99-435, 100 Stat. 1080.

7. 42 U.S.C. ch. 126 (1994). President Bush signed the ADA into law on July 26, 1990. *Id.* Senator Tom Harkin (D. Iowa), the chief sponsor of the ADA, often refers to the legislation as the "20th century Emancipation Proclamation for persons with disabilities." 136 CONG. REC. S9689 (daily ed. July 13, 1990).

8. Ticket to Work and Work Incentives Improvement Act of 1999, Pub. L. No. 106-170, 113 Stat. 1860; Individuals with Disabilities Education Act of 1997, Pub. L. No. 105-17, 111 Stat. 37; Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994, Pub. L. No. 103-230, 108 Stat. 284; Rehabilitation Act Amendments of 1992, Pub. L. No. 102-569, 106 Stat. 4344.

Many people have documented the historical mistreatment of persons with disabilities. Others have described and analyzed the ADA as a civil rights statute that prohibits discrimination in the areas of employment, public services, public accommodations, and telecommunications. Few people have stepped back to consider the fundamental beliefs and core policies that were reflected in the 1970s legislation, explicitly articulated in the ADA, and further refined in subsequent legislation. Taken as a whole, these efforts have critical implications regarding the design, implementation and evaluation of programs and policies that affect citizens with disabilities.

The purpose of this overview is to provide a Disability Policy Framework consistent with the “new paradigm” that can be used as a lens or guidepost<sup>9</sup> to design, implement, and evaluate generic,<sup>10</sup> as well as disability-specific, public policies and programs to ensure meaningful inclusion of people with disabilities in mainstream society.

To this end, this overview is targeted to the needs of several audiences. For federal, state, and local policymakers as well as persons with disabilities, their families and advocates, this overview offers a guidepost for designing, implementing, and assessing generic, as well as disability-related, programs and policies. For researchers, this overview provides a benchmark for studying the extent to which generic and disability-specific policies and programs reflect the “new paradigm” and achieve its goals. For service providers, this Appendix provides a lens for designing, implementing and evaluating the delivery of services to persons with disabilities. Finally, for college and university professors teaching courses that include disability policy, this overview provides a framework for policy analysis.

This overview is divided into two parts. Part I describes the various components of the Emerging Disability Policy Framework. Using the Emerging Disability Policy Framework described in Part I, Part II of the overview includes an audit—a checklist of questions that stakeholders can use to assess the extent to which generic and disability-specific programs or policies reflect the components of the Emerging Disability Policy Framework.

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9. See *Re-Charting the Course—First Report of the Presidential Task Force on Employment of Adults with Disabilities* (Nov. 15, 1998).

10. Generic programs include persons with and without disabilities among the beneficiaries of assistance. An example of a generic program is the recently enacted Workforce Investment Systems Act, 29 U.S.C. ch. 30 (Supp. IV 1998), that establishes an integrated workforce investment preparation and employment system for all job seekers, including individuals with disabilities.

**PART I**  
**AN OVERVIEW OF THE EMERGING DISABILITY POLICY FRAMEWORK**  
**INTRODUCTION**

Part I provides an overview of the major components of the Emerging Disability Policy Framework, including:

- Statement of Findings and Rationale
- Precept and Overarching Goals
- Definitions of Disability
- Core Policies
- Methods of Administration
- Program Support

**STATEMENT OF FINDINGS AND RATIONALE**

Every piece of disability-specific legislation promulgated since 1973 includes a carefully constructed rationale known as a "Statement of Findings." A well-constructed Statement of Findings includes the following four major items:

1. A description of the historical treatment of persons with disabilities;
2. A summary of the nature of the problem addressed by the proposed legislation;
3. An explanation of why the issue is important and why change is needed; and
4. A description of the role of various entities in designing, implementing, and evaluating the legislation.

A Statement of Findings facilitates enactment of the legislation by convincing policymakers of its merits. Once the legislation is enacted, the rationale provides a clear statement to guide implementation and enforcement of the law.<sup>11</sup>

**PRECEPT AND OVERARCHING GOALS**

In addition to the inclusion of a Statement of Findings, most major disability-specific legislation includes a statement of precept and goals. As with the Statement of Findings, a well-constructed precept and statement of goals further facilitates enactment of the legislation by convincing policymakers of the merits of the legislation. Once the legislation is enacted, the precept and goals provide clear statements to guide implementation of the law. In addition, the precepts and goals provide an explanation when there is uncertainty regarding legislative intent.

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11. See Individuals with Disabilities Education Act § 601, 20 U.S.C. § 1400(c) (1994 & Supp. IV 1998) (listing the congressional purpose as "assur[ing] that all children with disabilities" have access to appropriate legislation); Rehabilitation Act of 1973 § 100(a), 29 U.S.C. § 720(a) (1994 & Supp. IV 1998) (listing congressional findings, purpose, and policy behind the Act); ADA § 2(a), 42 U.S.C. § 12101(a) (1994) (listing congressional findings regarding disabled Americans).

The statements of precept and goals are either included within the Statement of Findings or within a separate section. They are sometimes referred to as a "Purpose" section or a "Statement of Policy."

The precept of Disability Policy Framework is that disability is a natural and normal part of the human experience that in no way diminishes a person's right to participate fully in all aspects of life, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of the individual.<sup>12</sup>

According to the Americans with Disabilities Act, "the Nation's proper goals regarding individuals with disabilities are to assure:

1. equality of opportunity,
2. full participation [empowerment],
3. independent living, and
4. economic self-sufficiency . . . ."<sup>13</sup>

## DEFINITIONS OF DISABILITY

In addition to constructing a Statement of Finding and the precept and overarching goals of the legislation, stakeholders must define who will be protected or benefited from the proposed legislation. All laws include definitions of key terms. The definition of the term "disability" within the specific legislation is drafted to accomplish its specific purposes. For example, civil rights statutes contain a definition of "disability" that enables the reader to determine which individuals will be protected by the legislation.<sup>14</sup> The definition of "person with a disability" is also included in formula grants and entitlement programs to determine which individuals are eligible for benefits or services.<sup>15</sup>

## CORE POLICIES

Once the rationale and goals for the proposed legislation are specified and definitions of disability are established, it is critical for stakeholders to specify the core policies. These statements describe the scope and limitations of the protections, the nature and type of

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12. See IDEA § 601(c)(1), 20 U.S.C. § 1400(c)(1) (1994) (explaining how disability is a "natural part of the human experience"); Rehabilitation Act of 1973 § 2(a)(3), 29 U.S.C. § 701(a)(3) (1994) (same); Developmental Disabilities Assistance and Bill of Rights Act § 101(a)(2), 42 U.S.C. § 6000(a)(2) (1994) (same).

13. ADA § 2(a)(8), 42 U.S.C. § 12101(a)(8) (1994).

14. Two civil rights statutes pertaining to persons with disabilities are of particular relevance. The first is the Americans with Disabilities Act, 42 U.S.C. ch. 126 (1994), and implementing regulations, 28 C.F.R. pt. 35 (1999), which prohibits discrimination by employers, state and local agencies, public accommodations, and telecommunications. The second law is section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1994), which prohibits discrimination by recipients of federal financial assistance. Pursuant to Executive Order 12250, the Department of Justice is responsible for coordinating the implementation of section 504 by various federal agencies, each of which is responsible for issuing its own section 504 regulation. The section 504 coordination regulations issued by the Department of Justice are set out in 28 C.F.R. pt. 41 (1999). The ADA definition of "disability" is set out in section 3(2) of the ADA, 42 U.S.C. § 12102(2) (1994). The section 504 definition of "individual with a disability" is set out in section 6(20) of the Rehabilitation Act of 1973, 29 U.S.C. § 705(20) (1994).

15. See, for example, the definition of "disability" for an adult in the Supplemental Security Income program, Social Security Act § 1614(a)(3)(A), 42 U.S.C. § 1382c(a)(3)(A) (1994) ("An individual shall be considered disabled . . . if he is unable to engage in any substantially gainful activity by reason of any medically determinable . . . impairment [lasting—or expected to last—no less than twelve months] . . ."). See also the definition included under Part B of the Individuals with Disabilities Education Act under which a child is entitled to special education and related services, IDEA § 602(3), 20 U.S.C. § 1401(3) (Supp. IV 1998) (defining children's disabilities as those encompassing mental retardation and learning disabilities, as well as health impairments and emotional disturbance).



benefits and services, and the circumstances under which benefits and services will be provided.

The numerous core policies can best be understood when they are organized under the four goals of disability policy articulated in the ADA—equality of opportunity, full participation (empowerment), independent living, and economic self-sufficiency. Core policies from various categories of legislation affecting people with disabilities are provided below.

### **A. EQUALITY OF OPPORTUNITY**

The goal of equality of opportunity (nondiscrimination) articulated in the ADA includes three core components: (1) individualization, (2) genuine, effective, and meaningful opportunity, and (3) inclusion and integration.

#### **1. Individualization**

This is accomplished through the following actions:

- Making decisions on the basis of the unique strengths, resources, priorities, concerns, abilities, and capabilities of each person with a disability, including individuals with significant disabilities.<sup>16</sup>
- Treating a person with a disability as an individual based on facts and objective evidence, and not based upon generalizations, stereotypes, fear, ignorance, prejudice, or pernicious mythologies.<sup>17</sup>
- Using definitions and eligibility criteria that result in even-handed treatment of a person with a particular disability and other similarly situated individuals, including nondisabled persons and persons with other disabilities.<sup>18</sup>
- Satisfying the broad, nondiscriminatory eligibility criteria by ensuring universal access to generic programs for persons with disabilities.<sup>19</sup>
- Using interdisciplinary assessments performed on a timely basis by qualified personnel conducted across multiple environments in making fact-specific decisions. Using information provided by the individual with a disability, the person's family, or the representative.<sup>20</sup>
- Developing individualized plans that identify and describe needs, goals, objectives, services, and accountability measures.<sup>21</sup>

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16. See Developmental Disabilities Assistance and Bill of Rights Act § 101(c)(3), 42 U.S.C. § 6000(c)(3) (1994) (providing that disabled people and their families should be the "primary decisionmakers" about what services they need).

17. S. REP. NO. 101-116, at 7 (1989).

18. See 28 C.F.R. § 35.130 (1999) (prohibiting a public entity from treating a disabled person unequally or providing substandard services); 28 C.F.R. § 41.51(b)(1) (1999) (prohibiting the same conduct as the previous regulation).

19. 28 C.F.R. § 35.130 (1999); 28 C.F.R. § 41.51(b)(1) (1999).

20. See IDEA § 614(a), 20 U.S.C. § 614(a), (*repealed by* Pub. L. No. 91-230, 84 Stat. 188 (1970); Rehabilitation Act of 1973 § 102, 29 U.S.C. § 722 (1994 & Supp. IV 1998) (stating that decisions will be made by agency officials within a reasonable period of time).

21. See Rehabilitation Act of 1973 § 102, 29 U.S.C. § 722 (1994 & Supp. IV 1998) (listing options for developing individualized plans for employment); IDEA § 614(c), 20 U.S.C. § 1414(c) (Supp. IV 1998), (*repealed by* Pub. L. No. 91-230, 84 Stat. 188 (1970)).

## 2. Genuine, Effective, and Meaningful Opportunity

Ensure that the opportunities that are made available to persons with disabilities are genuine, effective, and meaningful.<sup>22</sup> This includes the following actions:

- Providing “appropriate” services and supports that address the unique needs of the individual, not the needs of the “average” person.<sup>23</sup>
- Making reasonable modifications to policies, practices, and procedures, unless it would fundamentally alter the nature of the program.<sup>24</sup>
- Providing auxiliary aids and services, unless it would result in an undue hardship to the covered entity.<sup>25</sup>
- Providing reasonable accommodations to employees, unless it would result in an undue hardship to the covered entity.<sup>26</sup>
- Making programs physically accessible.<sup>27</sup>
- Providing accessible communications.<sup>28</sup>

## 3. Inclusion and Integration

Foster the inclusion and integration of persons with disabilities in programs, projects, and activities provided by covered entities. Persons with disabilities should not unnecessarily or unjustifiably be isolated, segregated, or denied effective opportunities to interact with nondisabled persons and to participate in mainstream activities. This can be accompanied by the following:

- Administering programs, projects, and activities in the most integrated setting appropriate to the needs of the individual.<sup>29</sup>
- Providing services in the least restrictive environment (continuum of program options).<sup>30</sup>

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22. See generally Nondiscrimination on the Basis of Disability, 28 C.F.R. § 35.130 (2000) (stating that no qualified individual shall be subject to discrimination by a public entity); Nondiscrimination on the Basis of Handicap, 28 C.F.R. § 41.51(b) (2000) (stating that handicapped individuals may not be denied opportunities by federally assisted programs on the basis of the handicap).

23. IDEA § 612(a)(1), 20 U.S.C. § 1412(a)(1) (1994 & Supp. IV 1998).

24. 28 C.F.R. § 35.130(b)(7) (1999); 28 C.F.R. § 41.51(b) (1999).

25. 28 C.F.R. § 35.160(b) (1999); 28 C.F.R. § 41.51(b), (e) (1999).

26. 29 C.F.R. § 1630.9 (1999); 28 C.F.R. § 41.53 (1999).

27. See 28 C.F.R. § 35.149-51 (1999) (addressing program accessibility in the ADA); 28 C.F.R. § 41.53 (1999) (containing the section 504 coordination regulations).

28. See 28 C.F.R. § 35.160(b) (1999) (discussing accessible communications in the ADA); 28 C.F.R. § 41.51(b), (e) (1999) (providing the section 504 coordination regulations).

29. See 28 C.F.R. § 35.130(d) (1999) (discussing integration); 28 C.F.R. § 41.51(d) (1999) (providing the section 504 coordination regulations).

30. See 34 C.F.R. §§ 300.550-.551 (1999) (addressing least restrictive environments within the implementation of IDEA).



## **B. FULL PARTICIPATION**

The second goal of disability policy articulated in the ADA is full participation. This means empowering persons with disabilities, fostering self-determination, allowing real and informed choice, and participating actively in decision-making processes at the individual and system level (including self-advocacy).<sup>31</sup>

### **1. Involvement and Choice by the Individual in Decisions Affecting the Individual**

Foster the active involvement and real and informed choice of the individual with a disability in decisions directly affecting the individual by encouraging the following:

- Opportunities to receive information about policies that affect the individual;
- Assessments of the individual's progress;
- Planning;
- Services and supports for the individual (including the right to refuse or terminate services); and
- Selection of service providers.<sup>32</sup>

### **2. Involvement and Choice by the Individual's Family in Decisions Affecting the Individual**

Facilitate active involvement and real and informed choice of family members (under appropriate circumstances) in decisions affecting the individual with a disability and the family, including the following:

- Opportunities to receive information about policies that affect the individual;
- Assessments of the individual's progress;
- Planning;
- Services and supports for the individual (including the right to refuse or terminate services); and
- Selection of service providers.<sup>33</sup>

### **3. Involvement by Individuals and Families at the System Level**

Encourage active involvement in policy decisions at the system level, including the following:

- Opportunities to comment on agency proposals and agency

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31. See Rehabilitation Act of 1973 § 2(c)(1), 29 U.S.C. § 701(c)(1) (Supp. IV 1998) (requiring that all programs receiving assistance be carried out in a manner consistent with "respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers, based on informed choice, of individuals with disabilities"); Developmentally Disabled Assistance and Bill of Rights Act § 101, 42 U.S.C. § 6000 (1994) (same).

32. See, e.g., IDEA § 614(d)-(f), 20 U.S.C. § 1414(d)-(f) (Supp. IV 1998); Rehabilitation Act of 1973 § 102(b), 29 U.S.C. § 722(b) (Supp. IV 1998) (requiring that the eligible individual participate in developing and agreeing to the rehabilitation program); Ticket to Work and Self-Sufficiency Program, Social Security Act as added by Pub. L. No. 106-170, 113 Stat. 1860 (same).

33. Ticket to Work and Self-Sufficiency Program, Social Security Act as added by Pub. L. No. 106-170, 113 Stat. 1860.

response;

- Participation in governing boards or councils that make or recommend policies relating to the program; and
- Joint sign-off between the public agency and the governing board or council.<sup>34</sup>

### **C. INDEPENDENT LIVING**

The third goal of disability policy articulated in the ADA is to foster the ability and capabilities of individuals with disabilities to live independently.

#### **1. Independent Living Skills Development and Specialized Planning**

Support independent living skill development and specialized planning, by the following:

- Training in individual and systems advocacy;
- Services related to securing food, clothing, and shelter;
- Management of personal assistants and other support personnel; and
- Use of assistive technology devices.<sup>35</sup>

#### **2. Long-Term Services and Supports, Including Personal Assistance Services and Supports**

Support for long-term services and supports, including personal assistance services and supports necessary to enable an individual to live independently in the community, including consumer-directed and agency-directed personal assistance services and supports.<sup>36</sup>

#### **3. Cash Assistance and other Forms of Support**

Support for cash assistance and other programs of assistance that enable the individual to live independently in the community include, for example:

- Cash assistance,<sup>37</sup>
- Health care,<sup>38</sup>

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34. See provisions in the Rehabilitation Act of 1973 pertaining to the State Rehabilitation Advisory Council, 29 U.S.C. § 725 (1994); Statewide Independent Living Council, 29 U.S.C. § 795(d) (1994); Ticket to Work and Work Incentives Advisory Panel, Pub. L. No. 106-170, 113 Stat. 1860.

35. 29 U.S.C. §§ 796, 796f (1994 & Supp. IV 1998).

36. See, e.g., 29 U.S.C. § 723 (1994 & Supp. IV 1998) (offering personal assistance services to those individuals receiving vocational rehabilitation services under the Rehabilitation Act of 1973 § 103); 42 U.S.C. § 1396d (1994) (amended 1999) (explaining that personal assistance services are an optional benefit under the Medicaid program); 42 U.S.C. § 1396n (1994) (amended 1999) (stating that assistance services are also an authorized benefit under the Medicaid home- and community-based services waiver).

37. See 42 U.S.C. § 1381 (1994) (authorizing the Supplemental Social Security Income program, a federally administered cash assistance program designed to provide minimum income for, among others, persons who are blind and disabled); 42 U.S.C. § 401(b) (1994) (initiating a program of federal disability insurance benefits for, among others, workers who have contributed to the Social Security trust fund and become disabled or blind before retirement age).

38. See generally 42 U.S.C. § 1396 (1994) (authorizing the Medicaid program).

- Transportation,
- Housing,<sup>39</sup> and
- Food.<sup>40</sup>

#### **D. ECONOMIC SELF-SUFFICIENCY**

The fourth goal of disability policy articulated in the ADA is to foster the economic security, stability, and productivity of persons with disabilities consistent with their actual (not perceived) capabilities, strengths, needs, interests, and priorities.

##### **1. Systems Providing Employment-Related Services and Supports**

Systems providing employment-related skills and supports include, for example:

- Education,<sup>41</sup>
- Training,<sup>42</sup>
- Self-employment (entrepreneurship),<sup>43</sup> and
- Ongoing assistance on-the-job.<sup>44</sup>

##### **2. Cash Assistance and Other Programs of Assistance**

Support for cash assistance and other programs, such as the following:

- Cash assistance, including worker incentive provisions;<sup>45</sup>
- Health care;<sup>46</sup>
- Housing;<sup>47</sup> and
- Food.<sup>48</sup>

##### **3. Tax Policy Providing Incentives**

Tax policy that provides incentives to employers, consistent with business objectives, to hire people with disabilities and that provides deductions and credits for employment-

39. See Housing Act of 1937 § 8, 42 U.S.C. § 1437f(o) (1999).

40. Food Stamp Act of 1977, 7 U.S.C. § 2011 (1994).

41. See Rehabilitation Act of 1973 § 103, 29 U.S.C. § 722 (1994 & Supp. IV 1998); IDEA, 20 U.S.C. § 1400 (1994 & Supp. IV 1998).

42. See Rehabilitation Act of 1973, 29 U.S.C. § 720 (1994).

43. *Id.*

44. See Social Security Act § 1915(c), 42 U.S.C. § 1396n(c) (1994) (amended 1999) (authorizing expenditures under the home-and community-based services waiver program).

45. Title XVI of the Social Security Act authorizes the Supplemental Security Income program, a federally administered cash assistance program designed to provide a minimum income for, among others, persons who are blind and disabled. 42 U.S.C. § 1381 (1994). Section 1619 of the Social Security Act creates incentives for SSI beneficiaries with disabilities to work, including permitting these individuals to retain eligibility for Medicaid. See 42 U.S.C. § 1382h (1994) (enabling these individuals to continue to receive personal assistance services). See also Social Security Act § 1905(q), 42 U.S.C. § 1396d(q) (1994); Social Security Act, U.S.C. § 401 (1994) (authorizing a program of federal disability insurance benefits for, among others, workers who have contributed to the Social Security trust fund and become disabled or blind before retirement age); Ticket to Work and Work Incentives Improvement Act of 1999, Pub. L. No. 106-170, 113 Stat. 1860 (amending the Social Security Act and Medicaid to create new work incentives and expand health care for workers with disabilities).

46. See generally 42 U.S.C. § 1396 (1994) (authorizing the Medicaid program).

47. See U.S. Housing Act of 1937 ch. 8, 42 U.S.C. § 1437f(o) (1994) (providing rental vouchers for low income families).

48. Food Stamp Act of 1977, 7 U.S.C. §§ 2011-2036 (1994 & Supp. IV 1998).

related expenditures enabling an individual with a disability to work include incentives for employers<sup>49</sup> and individuals with disabilities.

## **METHODS OF ADMINISTRATION**

After providing the rationale and goals for the proposed legislation, establishing definitions for disability, and specifying the core policies, stakeholders must then consider the inclusion of administrative or accountability provisions. These provisions, which are referred to as “methods of administration,” include such provisions as monitoring and enforcement to ensure implementation, procedural safeguards to ensure individuals are afforded due process of law, outcome measures to determine the impact of the legislation, and methods for financing programs.

These methods of administration are designed to maximize the likelihood that the protections afforded by the civil rights statutes are realized, and that the services and benefits made available under entitlement and grant-in-aid programs are provided and implemented in accordance with best practices. Examples of methods of administration from various categories of legislation affecting people with disabilities are provided below.

### ***A. STATE PLANS, APPLICATIONS, AND WAIVERS***

State plans and applications describe how the public agency plans to satisfy the applicable requirements, including core policies and methods of administration. Waivers provide exemptions or alternative methods of implementation, including testing the provision of new services.<sup>50</sup>

### ***B. MONITORING AND ENFORCEMENT BY GOVERNMENT AGENCIES***

Monitoring and enforcement maximizes the likelihood that recipients and contractors will comply with applicable requirements and implement the program to ensure results for persons with disabilities. This includes preparing monitoring instruments, conducting monitoring reviews, issuing reports, requiring corrective action, imposing sanctions, and securing remedies for individuals.<sup>51</sup>

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49. See 26 U.S.C. § 44 (1994) (providing a disabled access tax credit for small business); 26 U.S.C. § 51 (1994) (amended 1999) (providing a targeted jobs tax credit).

50. See generally the state plan requirements under the Rehabilitation Act of 1973, 29 U.S.C. § 721 (1994 & Supp. IV 1998); and the state (§ 612) and local (§ 613) eligibility provisions set out in IDEA, 20 U.S.C. §§ 1412-1413 (1994 & Supp. IV 1998). See also waiver provisions in section 1115 of the Social Security Act, 42 U.S.C. §§ 1215, 1396n(c), 1915(c) (1994 & Supp. IV 1998).

51. See, e.g., IDEA § 616, 20 U.S.C. § 1416 (1994 & Supp. IV 1998) (explaining withholding of payments and judicial review of educational discrimination against children with disabilities); 45 C.F.R. § 84.6 (1999); 28 C.F.R. §§ 35.170-190 (1999) (covering the filing of complaints for disability discrimination); 42 Fed. Reg. 22687 (May 4, 1997).

### **C. PROCEDURAL SAFEGUARDS**

Procedural safeguards for individuals include the following:

- The right to notice of rights;<sup>52</sup>
- The right to examine records;<sup>53</sup>
- The right to file a complaint;<sup>54</sup>
- The right to use of mediation and other forms of alternative dispute resolution;<sup>55</sup>
- The right to an administrative due process hearing and administrative review;<sup>56</sup> and
- The right to seek redress through private right of action in court, including remedies and the awarding of attorneys fees to prevailing parties.<sup>57</sup>

### **D. ACCOUNTABILITY FOR RESULTS (OUTCOME MEASURES)**

This area facilitates accountability for results using standards and performance indicators that reflect the expected outcomes for recipients with disabilities, the use of sanctions for failure to meet expected outcomes,<sup>58</sup> and rewards for exceeding expectations.<sup>59</sup>

### **E. REPRESENTATION AT THE INDIVIDUAL AND SYSTEMS LEVELS**

This area facilitates public support for representation and advocacy at the individual and systems level to ensure meaningful involvement and choice. This includes the following:

- Systems providing protection and advocacy at the individual and systems level;<sup>60</sup> and
- Self-advocacy training.<sup>61</sup>

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52. IDEA § 615(b)(3), 20 U.S.C. § 1415(b)(3) (1994 & Supp. III 1997) (giving a disabled person the opportunity to present complaints); 28 C.F.R. § 35.105 (1999).

53. IDEA § 615(b)(1), 20 U.S.C. § 1415(b)(1) (1994 & Supp. III 1997).

54. 28 C.F.R. §§ 35.170-190 (1999); *see* IDEA § 615(b)(6), 20 U.S.C. § 1415(b)(6) (1994 & Supp. III 1997); Rehabilitation Act of 1973 § 102(d), 29 U.S.C. § 722(d) (1994 & Supp. IV 1998) (requiring state agencies to provide written policies and procedures).

55. IDEA § 615(e), 20 U.S.C. § 1415(e) (1997); ADA § 513, 42 U.S.C. § 12212 (1994 & Supp. IV 1998);

56. IDEA § 615(f), 20 U.S.C. § 1415(f) (1994 & Supp. III 1997).

57. IDEA § 615(i), 20 U.S.C. § 1415(i) (1994 & Supp. III 1997); Rehabilitation Act of 1973 § 505, 29 U.S.C. § 795 (1994) (amended 1998); ADA § 203, 42 U.S.C. § 12133 (1994 & Supp. III 1997).

58. IDEA § 614 (d), 20 U.S.C. § 1414(d) (1994 & Supp. III 1997); Rehabilitation Act of 1973 § 106(c), 29 U.S.C. § 726(c) (1994 & Supp. IV 1998).

59. *See* 20 C.F.R. § 666.20(a) (1999) (expounding the regulations for implementing the Workforce Investment Act).

60. For example, protection and advocacy systems are funded under the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §§ 6041-6043 (1994 & Supp. IV 1998), the Rehabilitation Act of 1973, 29 U.S.C. § 794e (1994) (amended 1998), and the Protection and Advocacy for Mentally Ill Individuals Act, 42 U.S.C. §§ 10801-10851 (1994 & Supp. IV 1998). In addition, advocacy and individual representation is authorized under Title VII of the Rehabilitation Act of 1973, 29 U.S.C. § 796f-4 (1994) (amended 1998); parent training and information centers are authorized under IDEA, 20 U.S.C. § 1482 (Supp. III 1997). *See* Ticket to Work Incentives Improvement Act of 1999, Pub. L. No. 106-170, 113 Stat. 1860 (setting out state grants to protection advocacy systems for work incentives assistance to disabled beneficiaries).

61. For example, self-advocacy training is authorized under Title VII of the Rehabilitation Act of 1973, 29 U.S.C. § 796f-4 (1994) (amended 1998). In addition, parent training is authorized under the IDEA, 20 U.S.C. § 1482 (Supp. III 1997). It also is an authorized use under the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §§ 6000-6083 (1994 & Supp. IV 1998).

## ***F. SINGLE LINE OF RESPONSIBILITY, COORDINATION, AND LINKAGES AMONG AGENCIES***

It is beneficial to place accountability for the administration of a program in a single agency to avoid “buckpassing.”<sup>62</sup> At the same time, it is necessary to provide mechanisms for interagency coordination and collaboration to ensure that no one “falls between the cracks” and that agencies provide for the effective delivery of services.<sup>63</sup>

## ***G. SERVICE COORDINATION (CASE MANAGEMENT)***

It is essential to provide service coordination to assist individuals in receiving necessary services when a comprehensive array of services is required and such services are provided or paid for by multiple agencies.<sup>64</sup>

## ***H. FINANCING SERVICE DELIVERY***

This area includes proscribing methods for financing services through the allocation of funds or the establishment of cost reimbursement schemes (including outcome-based reimbursement schemes) that have the effect of denying effective opportunities for persons with the most significant needs.<sup>65</sup>

## ***I. PRIVACY, CONFIDENTIALITY, ACCESS TO RECORDS, AND INFORMED CONSENT***

Protecting privacy and confidentiality and requiring informed consent minimizes the extent of government intrusion.<sup>66</sup> Access to records assures that individuals have the necessary information to make informed choices.<sup>67</sup>

## ***J. COMPREHENSIVE SYSTEM OF PERSONNEL DEVELOPMENT***

Personnel who provide services to beneficiaries must satisfy qualification standards to perform assigned tasks in an effective and efficient manner. Personnel knowledgeable about civil rights statutes and promising practices are preferred because they are able to provide state-of-the-art services to persons with disabilities.<sup>68</sup>

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62. IDEA § 612(a)(11), 20 U.S.C. § 1412(a)(11) (1994) (amended 1997); Rehabilitation Act of 1973, § 101 (a)(2), 29 U.S.C. § 721(a)(2) (1994).

63. See Rehabilitation Act of 1973 § 101(a)(11), 29 U.S.C. § 721(a)(11) (1994) (providing for interagency cooperation); IDEA § 612(a)(12), 20 U.S.C. § 1412(a)(12) (1994 & Supp. IV 1998) (charging the Chief Executive Officer with ensuring interagency cooperation).

64. See the early intervention program in Part C of IDEA, 20 U.S.C. § 1435(a) (Supp. IV 1998).

65. See IDEA § 612(a)(5), 20 U.S.C. § 1412(a)(5) (1994 & Supp. IV 1998) (specifying that state funding schemes may not result in placing a child outside the least restrictive environment).

66. See, e.g., IDEA § 614(a)(1)(c), 20 U.S.C. § 1414(a)(1)(c) (Supp. IV 1998) (requiring parental consent for a qualification evaluation of a child); IDEA § 617(c), 20 U.S.C. § 1417(c) (1994 & Supp. IV 1998) (assuring confidentiality of personal information); ADA § 102(c)(3)(B), 42 U.S.C. § 12112(c)(3)(B) (1994 & Supp. IV 1998) (requiring that employers keep disability-related medical records confidential).

67. See 42 U.S.C. § 6042(g) (1994 & Supp. IV 1998) (authorizing a state's system to have access to individual records to address the needs of disabled individuals).

68. See IDEA § 612(a)(14)-(15), 20 U.S.C. § 1412(a)(14)-(15) (1994 & Supp. IV 1998) (mandating that states put into effect personnel standards and a system of personnel development); Rehabilitation Act of 1973 § 101(a)(7)(A), 29 U.S.C. § 721(a)(7)(A) (1994) (requiring that the state's plan establish standards of care for people with disabilities).



## ***K. RESPONSIVENESS TO CULTURAL DIVERSITY***

Services must be provided in a culturally competent manner and be responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals receiving services to ensure maximum participation in the program.<sup>69</sup>

## ***L. FISCAL PROVISIONS***

Public agencies must use program funds to supplement—and not supplant—other sources of funding and must maintain their own fiscal effort.<sup>70</sup>

## ***M. FINANCIAL MANAGEMENT AND REPORTING***

Grant funds should be managed in such a way to ensure fiscal control and fund accounting.<sup>71</sup>

## **PROGRAM SUPPORT**

Stakeholders provide the rationale and goals for the proposed legislation, establish definitions for disability, specify the core policies, and develop methods of administration provisions. In addition, stakeholders must ensure that initiatives conform to best practices and are state-of-the-art by adopting program supports, such as grants, to support systemic change, research, training, and technical assistance. Examples of program supports from various categories of legislation affecting people with disabilities are provided below.

### ***A. SYSTEMS CHANGE INITIATIVES***

This includes funding designed to assist public agencies in developing and implementing comprehensive reforms at the system or institutional level (policies, practices, and procedures).<sup>72</sup>

### ***B. TRAINING OF INDIVIDUALS WITH DISABILITIES AND THEIR FAMILIES***

This area requires supporting model approaches for training individuals with disabilities and their families.<sup>73</sup>

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69. See Rehabilitation Act of 1973 § 101, 29 U.S.C. § 721 (1994 & Supp. IV 1998) (describing outreach procedures to identify and serve individuals with disabilities who are minorities).

70. See IDEA § 612(a)(18)-(19), 20 U.S.C. § 1412(a)(18)-(19) (1994 & Supp. IV 1998) (outlining the rules for public agencies regarding allocation of funding).

71. See 20 U.S.C. § 1232(f) (1994) (defining how records are to be kept).

72. See 20 U.S.C. §§ 1451-1456 (1994 & Supp. IV 1998) (providing assistance in the area of media); 29 U.S.C. § 3001 (1994) (encompassing technological assistance); 42 U.S.C. ch. 75 (1994) (codifying developmental assistance); Ticket to Work and Work Incentives Improvement Act of 1999, Pub. L. No. 106-170, 113 Stat. 1862 (developing grants to establish state infrastructure that will support working individuals with disabilities).

73. See, e.g. 20 U.S.C. §§ 1461, 1462, 1471-1474 (1994), *amended by* 1461, 1471-1474 (Supp. IV 1998) (explaining parent information and training centers); 29 U.S.C. § 796f (1994 & Supp. IV 1998) (explaining centers for independent living under Title VII of the Rehabilitation

### ***C. TRAINING OF PERSONNEL REGARDING PROMISING PRACTICES***

This legislation provides support for personnel preparation and training, including training of specialists, generalists, and leaders.<sup>74</sup>

### ***D. RESEARCH, TECHNICAL ASSISTANCE, AND INFORMATION DISSEMINATION***

This area includes support research, technical assistance, and information dissemination which all ensure that the programs are effective, state-of-the-art, and efficient.<sup>75</sup>

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Act of 1973); 42 U.S.C. ch. 75 (1994) (explaining protection and advocacy systems and university affiliated programs under the Developmental Disabilities Assistance and Bill of Rights Act); *see also* Ticket to Work and Work Incentives Improvement Act of 1999, Pub. L. No. 106-170, 113 Stat. 1860 (detailing Work Incentives Outreach programs under the Social Security Act).

74. *See* 20 U.S.C. §§ 1461, 1462, 1471-1474 (1994), *amended by* 20 U.S.C. §§ 1461, 1471-1474 (Supp. IV 1998) (covering training in education); 29 U.S.C. §§ 770-776 (1994 & Supp. IV 1998) (providing general training programs); 42 U.S.C. §§ 6061-6066 (1994 & Supp. IV 1998) (addressing interdisciplinary training by university affiliated programs under the Developmental Disabilities Assistance and Bill of Rights Act).

75. *See* 20 U.S.C. §§ 1451-1456, 1461, 1471-1474 (1994 & Supp. IV 1998) (regarding assistance in the field of media); 29 U.S.C. §§ 760-765 (1994 & Supp. IV 1998) (funding research by the National Institute on Disability and Rehabilitation Research under Title II of the Rehabilitation Act of 1973).



## **PART II**

### **GENERAL QUESTIONS FOR ANALYZING THE EXTENT TO WHICH DISABILITY-SPECIFIC OR GENERIC PROGRAMS OR POLICIES REFLECT THE DISABILITY POLICY FRAMEWORK**

#### **INTRODUCTION**

Using the Disability Policy Framework described in Part I of Appendix 1, this part includes general questions for analyzing the extent to which disability-specific and generic programs or policies reflect the precept, goals, definitions, core policies, methods of administration, and program supports set out in the Disability Policy Framework. In other words, this part of this Appendix serves as a guidepost for evaluating, expanding, and improving the design and implementation of public policies affecting persons with disabilities.

Answering these questions may entail, among other things, reviewing previous studies and reports, reviewing data, conducting analyses of proposed and final policy pronouncements, and conducting surveys of stakeholders. Not all questions articulated in this part are applicable to all programs and policies; for example, some questions may only be applicable to generic programs serving nondisabled persons, as well as persons with disabilities.

#### **QUESTIONS RELATING TO STATEMENT OF FINDINGS AND RATIONALE**

Is the program longstanding, undergoing major reform, or new? If new, does it replace an existing program?

Was the program established on a sound premise?

Has the program historically excluded persons with disabilities or specific categories of persons with disabilities? For example, has a policy, procedure, or accepted practice historically disqualified persons with significant disabilities from receiving services, or has a policy, procedure or accepted practice by a generic program automatically referred all persons with disabilities to disability-specific programs?

Is there a history of segregation of persons with disabilities into specific slots or components of the program?

Is there a history of denial of genuine, effective, and meaningful services in the program?

Is there a history of ensuring that people with disabilities enjoy choice in assessments, planning, services provided, selection of service providers, and measures of progress?

Is there history of fostering independent living and ensuring self-sufficiency?

What efforts have been made to ascertain the prevalence of persons with disabilities among the prospective pool of eligible recipients of a generic program?

What efforts have been made to ascertain the scope of unmet need?

Is the public agency considering the historical treatment of persons with disabilities in the development of new policies and procedures and in the methods of administration it uses?

### **QUESTIONS RELATING TO PRECEPT**

Does the program include a statement articulating the core precept on which it is based? Is the core precept of the program consistent with the precept of disability policy that disability is a natural and normal part of the human experience that in no way diminishes a person's right to fully participate in the program, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of the individual?

### **A QUESTION RELATING TO OVERARCHING GOALS**

Do the goals of the program reflect the goals of federal disability policy articulated in the ADA—equality of opportunity, full participation (empowerment), independent living and economic self-sufficiency for persons with disabilities?

### **QUESTIONS RELATING TO DEFINITION OF DISABILITY**

Does the definition of disability reflect the purposes of the particular legislation?

How does the definition of disability relate to definitions used in other programs?

Does it relate to the definition used in section 504 and the ADA?

### **QUESTIONS RELATING TO CORE POLICIES**

#### ***A. QUESTIONS RELATING TO EQUALITY OF OPPORTUNITY***

##### **1. Individualization**

Do the policies and procedures governing eligibility and application for and

delivery of services under the program:

Account for the unique strengths, resources, priorities, concerns, abilities, and capabilities of each person with a disability, including individuals with significant disabilities?

Account for the added dimension of poverty?

Use definitions and eligibility criteria that result in even-handed treatment between a person with a particular disability and other similarly situated individuals, including nondisabled persons and persons with other disabilities?

Satisfy the broad, nondiscriminatory eligibility criteria by ensuring universal access to generic programs for persons with disabilities?

Support and promote the treatment of persons with a disabilities as individuals based on facts and objective evidence, not based on generalizations, stereotypes, fear, ignorance, or prejudice?

Use interdisciplinary assessments performed by qualified personnel, conduct timely assessments across multiple environments, and use information provided by the individual with a disability and the person's family or representative in making fact-specific decisions?

Use individualized plans to identify and describe needs, goals, objectives, services, and accountability measures?

## 2. Genuine, Effective, and Meaningful Opportunity

Do the policies and procedures governing eligibility and application for and delivery of services under the program offer opportunities that are genuine, effective, and meaningful? Do the policies and procedures:

Provide "appropriate" services and supports designed to meet the unique needs of the individual, not the needs of the "average" person?

Make reasonable modifications to policies, practices, and procedures, unless it would fundamentally alter the nature of the program?

Provide auxiliary aids and services, unless it would result in an undue hardship to the covered entity?

Provide reasonable accommodations to employees, unless it would result in an undue hardship to the covered entity?

Make a program physically accessible?

Provide for communication accessibility?

### 3. Inclusion and Integration

Do the policies and procedures governing eligibility and application for and delivery of services under the program foster the inclusion and integration of persons with disabilities, or do the policies and procedures unnecessarily or unjustifiably isolate or segregate persons with disabilities?

#### ***B. A QUESTION RELATING TO FULL PARTICIPATION***

Do the policies and procedures governing the program foster the empowerment of persons with disabilities, real and informed choice, and active participation in decision-making processes at the individual and system level (including self-advocacy)?

More specifically, do the policies and procedures governing the program foster:

Active involvement and real and informed choice of the individual with a disability in areas including:

Opportunity to receive information about policies that affect the individual?

Assessments?

Planning?

Services?

Selection of service providers?

Measures of progress?

Active involvement and real and informed choice of family members and other representatives (under appropriate circumstances) in decisions affecting the individual with a disability and the family, including:

Opportunity to receive information about policies that affect the individual?

Assessments?

Planning?

Services?

Selection of service providers?

Measures of progress?

Active involvement in policy decisions at the system level (respecting the design, implementation and evaluation of a program), including:

- Consideration of input from consumers?
- Participation on governing boards and councils?
- Joint sign-off on policies by the governing board/council?

### ***C. QUESTIONS RELATING TO INDEPENDENT LIVING***

Do the policies and procedures governing the program foster the ability and capabilities of individuals with disabilities to live independently through support for independent living skill development, including:

- Training in individual and systems advocacy?
- Service related to securing food, clothing, and shelter?
- Training the management of personal assistants and the use of assistive technology?
- Specialized planning for transitioning to independent living?

Do the policies and procedures governing the program enable the person with a disability to live independently through the provision of long-term services and supports, for example, consumer-directed personal assistance services and supports and assistive technology devices and services?

Do the policies governing the program enable the person with a disability to live independently in the community through cash assistance or other forms of assistance?

### ***D. QUESTIONS RELATING TO ECONOMIC SELF-SUFFICIENCY***

Do the policies and procedures governing the program foster the economic security, stability, and productivity of persons with disabilities consistent with their actual (not perceived) capabilities, strengths, needs, interests, and priorities through support for:

- Systems that include universal access to generic services as well as access to specialized services and supports as an integral component of the system?
- Training, education, and employment of choice (including self-employment)?
- Ongoing supports on-the-job?
- Specialized planning (e.g., transition planning for children in high school)?
- Cash assistance programs that reflect the goal of maximizing economic self-sufficiency, including policies that provide incentives to work (e.g., waive or modify income and resource limits, and retain eligibility for acute and long-term services and supports)?

## **QUESTIONS RELATING TO METHODS OF ADMINISTRATION**

### ***A. QUESTIONS RELATING TO STATE AND LOCAL PLANS, APPLICATIONS, AND WAIVERS***

Does the plan/application include specific policies and procedures governing implementation for persons with disabilities?

Do waiver requests have the effect of enhancing or diminishing opportunities for persons with disabilities? For example, is a waiver request designed to test new strategies for delivering services that reflect the goals of disability policy articulated in the ADA? Or is the waiver request based on "perceptions" that individuals with disabilities cannot succeed or participate in the program or assessment generally applicable to nondisabled persons?

Does the plan/application explain how people with disabilities and their representatives were involved in the process of completing the plan/application?

In addition to the inclusion of an assurance of nondiscrimination, does the plan/application include specific policies and procedures relating to implementation of the program consistent with section 504 of the Rehabilitation Act of 1973 and the ADA?

### ***B. QUESTIONS RELATING TO MONITORING AND ENFORCEMENT BY GOVERNMENT AGENCIES***

What are the respective roles and responsibilities of federal, state, and local agencies for monitoring and enforcement?

Does the monitoring instrument developed by the government agency include specific inquiries related to persons with disabilities? If so, what are they?

Does the government agency use a monitoring instrument for ascertaining compliance with section 504 of the Rehabilitation Act of 1973 and the ADA? If so, what is included?

Do on-site monitoring reviews include assessments relating to meeting the needs of persons with disabilities and ensuring nondiscrimination?

What sanctions are available and used? Under what circumstances?

What incentives are available and used?

How are findings of noncompliance used by the agency? Are findings of noncompliance used for purposes of ongoing continuous quality improvement reviews?

What remedies are available?

Is there a complaint resolution procedure that includes complaints involving discrimination on the basis of disability?

***C. QUESTIONS RELATING TO PROCEDURAL SAFEGUARDS FOR INDIVIDUALS,  
THEIR FAMILIES, AND REPRESENTATIVES***

Do the policies and procedures governing the program provide for:

Notice of rights?

Examination of records?

The right to file a complaint?

The use of mediation and other forms of alternative dispute resolution?

Administrative due process hearings and administrative review?

Redress through private right of action in court, including remedies and the awarding of attorneys' fees to prevailing parties?

***D. QUESTIONS RELATING TO ACCOUNTABILITY FOR RESULTS (OUTCOME MEASURES)***

Does the agency include outcome measures that address issues of specific relevance to persons with disabilities?

Does the agency disaggregate data so the agency can determine whether its program is meeting the needs of persons with disabilities or persons with specific categories of disabilities as part of a process of continuous improvement?

***E. QUESTIONS RELATING TO REPRESENTATION AT THE INDIVIDUAL AND SYSTEMS LEVEL***

Does the public agency provide support for representation and advocacy at the individual and systems level, including support for systems providing protection and advocacy, and self-advocacy training?

***F. QUESTIONS RELATING TO SINGLE LINE OF RESPONSIBILITY/COORDINATION  
AND LINKAGES AMONG AGENCIES***

Is there a single agency (state or local) responsible for implementation of the program for all beneficiaries, including persons with disabilities? If not, how does the agency ensure compliance for persons with disabilities?

Does the agency require the assignment of an individual who will be responsible for ensuring implementation of the program for persons with disabilities, particularly with respect to implementation of the program consistent with section 504 of the Rehabilitation Act of 1973 and the ADA?



Has the agency developed policies and procedures for collaboration among agencies to ensure meaningful and effective delivery of necessary services to persons with disabilities, including cost sharing arrangements?

***G. A QUESTION RELATING TO SERVICE COORDINATION (CASE MANAGEMENT)***

Has the agency developed policies and procedures for service coordination to ensure that individuals with disabilities, particularly those with the most significant disabilities, receive the services they need, particularly where services are provided by multiple agencies?

***H. QUESTIONS RELATING TO FINANCING SERVICE DELIVERY***

Does the system for allocating funds among agencies and service providers facilitate or thwart accomplishment of the goals articulated in the ADA and the policies that effectuate the goals? For example, does the outcome-based reimbursement scheme used to pay service providers recognize and reward those who serve persons with the most significant disabilities and who cost more than the average recipient of services (risk adjustment)?

Is the network of service providers adequate to address the needs of persons with disabilities eligible for assistance under the program?

Is the financing system for services (for example, personal assistance services, assistive technology) consumer-directed?

***I. QUESTIONS RELATING TO PRIVACY, CONFIDENTIALITY, ACCESS TO RECORDS,***

***II. AND INFORMED CONSENT***

Does the agency include specific policies and procedures protecting the rights of persons with disabilities to privacy? Confidentiality? Access to records?

Does the agency include specific policies and procedures requiring informed consent?

***J. QUESTIONS RELATING TO COMPREHENSIVE SYSTEM OF PERSONNEL DEVELOPMENT***

Does the agency include specific training components regarding the implementation of its program (e.g., policy, "promising practices," and resource allocation) for persons with disabilities?

Does the agency include specific training for its personnel regarding implementation of its program consistent with section 504 of the Rehabilitation Act of 1973 and the ADA?



***K. A QUESTION RELATING TO RESPONSIVENESS TO CULTURAL DIVERSITY***

Does the agency include policies and procedures that address the special needs of persons with disabilities from diverse cultural backgrounds?

***L. A QUESTION RELATING TO FISCAL PROVISIONS***

Do the “supplement, not supplant” and “maintenance of effort” provisions ensure continuation of funding from state and local sources for services provided to persons with disabilities?

***M. QUESTIONS RELATING TO FINANCIAL MANAGEMENT AND REPORTING***

Do the fiscal control and fund accounting procedures enable oversight with respect to the provision of funding for persons with disabilities consistent with legislative intent?

**QUESTIONS RELATING TO PROGRAM SUPPORT**

To the extent an agency supports efforts to improve the quality of services provided through initiatives (such as systems change grants, training, research, technical assistance, demonstrations, and information dissemination), do these initiatives include specific components or specific initiatives that address the unique needs of persons with disabilities?

## APPENDIX 2

### MAJOR DISABILITY-RELATED LEGISLATION 1956-2000

#### 1956 - Social Security Amendments of 1956 (P.L. 84-880)

Established the Disability Insurance Trust Fund under Title II of the Social Security Act and provided for payment of benefits to workers with disabilities under the Social Security Disability Insurance program. Benefits were limited to workers age fifty and older.

#### 1958 - Captioned Films for the Deaf Act (P.L. 85-905)

Permitted the Office of Education to purchase, lease, or accept films (primarily recreational films), provide captions for them, and distribute them through state schools for the deaf, as well as through other appropriate state agencies.

#### 1960 - Social Security Amendments of 1960 (P.L. 86-778)

Eliminated the limitation on benefits to workers over age fifty (1956), and encouraged workers by authorizing a nine-month trial work period during which the beneficiary could have earnings without jeopardizing benefits.

#### 1963 - Social Security Act Amendments of 1963 (P.L. 88-156)

Established a new project grant program to improve prenatal care for women from low income families for whom the risk of mental retardation and other birth defects was known to be inordinately high. In addition, authorizations for grants to the states under the Maternal and Child Health and Crippled Children's programs (originally established in 1935 under P.L. 74-271) were increased and a research grant program was added.

#### 1963 - Mental Retardation Facilities Construction Act of 1963 (P.L. 88-164)

Authorized federal support for the construction of mental retardation research centers, university-affiliated training facilities, and community service facilities for children and adults with mental retardation.

#### 1965 - Elementary and Secondary Education Act of 1965 (P.L. 89-10)

The core of the Act, Title I, authorized a multi-billion dollar program of aid to assist the states and local school districts in providing compensatory education to educationally disadvantaged children residing in low-income areas.

#### 1965 - Social Security Act Amendments of 1965 (P.L. 89-97)

Title XVIII (Medicare) authorized health insurance benefits for eligible elderly persons or eligible persons with disabilities. Direct payments are made for medical services on behalf of eligible participants through "fiscal intermediaries," for example, private health insurance companies. "Part A" reimbursed hospitals and other covered entities. "Part B" provided supplemental medical insurance benefits. Title XIX authorized grants-in-aid to the states for the establishment of a medical assistance program to improve the accessibility and quality of medical care for low-income individuals (Medicaid).

#### 1965 - Elementary and Secondary Education Act Amendments of 1965 (P.L. 89-313)

Authorized aid to state agencies operating and/or supporting schools for children with disabilities.

#### 1966 - Library Services and Construction Act Amendments of 1966 (P.L. 89-511)

Authorized assistance for students with physical or mental disabilities who were in residential schools operated or substantially supported by the state. Part B of Title IV of the Act made federal funds available to state agencies for library services for individuals who were certified by a responsible authority as unable to read or to use conventional printed materials as a result of physical limitations. Such services could be provided through public or nonprofit library agencies or organizations.

#### 1966 - Military Medical Benefits Act Amendments of 1966 (P.L. 89-614)

Expanded health care benefits for dependents of active duty members of the uniformed services (the Army, Navy, Marine Corps, Air Force, Coast Guard, and the commissioned corps of Public Health Service). Under the expanded benefits of the Civilian Health and Medical Program of the Uniformed Services Program (CHAMPUS) for the handicapped, the spouse or child of an active duty member is eligible for services if he or she has a serious physical disability or is moderately to severely mentally retarded.

#### 1967 - Mental Retardation Amendments of 1967 (P.L. 90-170)

Authorized federal funds to assist in the cost of initiating services in community mental retardation facilities.

#### 1967 - Elementary and Secondary Education Act Amendments of 1967 (P.L. 90-247)

Expanded instructional media programs to provide for the production and distribution of educational media for the use of persons with all types of disabling conditions (not just deafness), their parents, actual or potential employers, and other persons directly involved in working on behalf of persons with disabilities.

#### 1967 - Social Security Act Amendments of 1967 (P.L. 90-248)

Added a list of mandatory and optional services under the Medicaid program and required participating states to offer early and periodic screening, diagnosis, and treatment services to all Medicaid-eligible children.

#### 1968 - National School Lunch Act and Child Nutrition Act of 1968 (P.L. 90-302)

The child care component provided federal assistance for meals served in institutions providing nonresidential day care for children. Facilities eligible to participate included day care centers, settlement houses, recreation centers, and institutions providing day care for youngsters with disabilities.

#### 1968 - Architectural Barriers Act of 1968 (P.L. 90-480)

Required buildings and facilities designed, constructed, altered, or financed by the federal government after 1969 to be accessible to and usable by persons with disabilities.

#### 1968 - Vocational Education Act Amendments (P.L. 90-576)

Required each state to earmark ten percent of its basic grant for services for youth with disabilities.

#### 1970 - Elementary and Secondary Education Act Amendments of 1970 (P.L. 91-230)

Created a separate Act, The Education of the Handicapped Act (EHA). Part B authorized grants to states to assist them in initiating, expanding, and improving programs for the education of children with disabilities. EHA also established several competitive grant programs such as personal preparation, research, and demonstration.

#### 1970 - Urban Mass Transportation Act Amendments of 1970 (P.L. 91-453)

Required eligible local jurisdictions to plan and design mass transit facilities and services so that they would be accessible to and useable by people with disabilities.

#### 1970 - Developmental Disabilities Services and Facilities Construction Amendments of 1970 (P.L. 91-517)

Included broad responsibilities for a state planning and advisory council to plan and implement a comprehensive program of services for persons with developmental disabilities. In addition, the legislation authorized grants to support interdisciplinary training in institutions of higher education of personnel providing services to persons with developmental disabilities (currently known as university-affiliated programs).

#### 1971 - Amendments to Title XIX of the Social Security Act (Medicaid Program) (P.L. 92-223)

Authorized public mental retardation programs to be certified as intermediate care facilities and requires that these programs offer, among other things, "active treatment."

#### 1972 - Small Business Act Amendments of 1972 (P.L. 92-595)

Expanded the authority of the Small Business Administration to provide direct and guaranteed loans for nonprofit sheltered workshops employing persons with disabling conditions and individuals with disabilities interested in establishing their own businesses.

#### 1972 - Social Security Amendments of 1972 (P.L. 92-603)

Repealed existing public assistance programs and added in their place a new Title XVI (Supplemental Security Income, SSI) program. This program authorizes cash benefits for individuals and couples who are aged, blind, or disabled. In addition, children under eighteen years of age with disabilities or blindness are eligible for benefits, provided that their disabilities were comparable in severity to adult recipients. Medicare coverage was authorized for Social Security beneficiaries with disabilities after they fulfilled a specified waiting period.

#### 1973 - Social Security Disability Act Amendments of 1973 (P.L. 93-66)

Tied increases in benefit levels under the disability insurance program to the Consumer Price Index, thus authorizing automatic annual cost-of-living adjustments in benefit payments.

#### 1973 - Federal-Aid Highway Act of 1973 (P.L. 93-87)

Authorized the use of funds under the Highway Program “to provide adequate and reasonable access for the safe and convenient movement of physically handicapped persons, such as across curbs constructed or replaced at all pedestrian crosswalks throughout the states.” Improvement funds may also be used for providing accessible rest stop facilities.

#### 1973 - Rehabilitation Act of 1973 (P.L. 93-112)

Included a complete revision of the state formula grant supporting the vocational rehabilitation program and the competitive programs supporting personnel development, research, and demonstrations. In addition, the legislation, among other things, adds “Section 502,” which established the Architectural and Transportation Barriers Compliance Board to enforce the Architectural Barriers Act of 1968 and provide technical assistance to agencies subject to section 504 regulations. In addition, the legislation adds “Section 504,” which prohibited discrimination against otherwise qualified persons with disabilities in any program or activity receiving federal funds.

#### 1973 - Amtrak Improvement Act of 1973 (P.L. 93-146)

The National Railroad Passenger Corporation was directed to take all steps necessary to ensure that no elderly or handicapped individual is denied intercity transportation on any passenger train operated by or on behalf of the Corporation. Steps include: acquiring special equipment and devices and conducting special training for employees; designing and acquiring new equipment and facilities and eliminating architectural and other barriers in existing equipment or facilities; and providing special assistance to persons who are elderly or disabled while boarding and alighting and within terminal areas.

#### 1974 - Housing and Community Development Amendments of 1974 (P.L. 93-383)

Expanded the low-income rent subsidy program under “Section 8” to include families consisting of single persons with disabilities. The legislation also extended the “Section 202” direct loan program to nonprofit agencies to projects for persons with mental as well as physical disabilities.

#### 1974 - Elementary and Secondary Education Amendments of 1974 (P.L. 93-380)

Included amendments to Part B of the Education of the Handicapped Act (EHA) that laid the basis for comprehensive planning, the delivery of additional financial assistance to the states, and the protection of handicapped children’s rights.

#### 1974 - Urban Mass Transportation Act Amendments of 1974 (P.L. 93-503)

Required project applicants to assure that the fares charged to the elderly or persons with disabilities during nonpeak hours do not exceed one-half of generally applicable rates for other riders during peak hours. In addition, localities were permitted under this Act to transport riders who are elderly or disabled free of charge and still be eligible for federal grant aid.

#### 1974 - Community Services Act (P.L. 93-644)

Stipulated that ten percent of children enrolled in the Head Start program must be children with disabilities.

#### 1974 - Social Services Amendments of 1974 (P.L. 93-647)

Consolidated social service grants to states under a new Title XX of the Social Security Act.

#### 1975 - Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103)

Created a "bill of rights" for persons with developmental disabilities, funded services for persons with developmental disabilities, added a new funding authority for university affiliated facilities, and established a system of protection and advocacy organizations in each state.

#### 1975 - Education for All Handicapped Children Act (P.L. 94-142)

Amended the Education of the Handicapped Act to mandate a free appropriate public education for all children with disabilities in a state, regardless of the nature or severity of the child's disability (Part B of the Education of the Handicapped Act).

#### 1977 - Tax Reduction and Simplification Act (P.L. 95-30)

Congress authorized a special tax credit to induce businesses to hire certain categories of chronically unemployed workers, disadvantaged youth, welfare recipients, and other hard to place persons, including individuals with disabilities.

#### 1977 - Legal Services Corporation Act Amendments of 1977 (P.L. 95-222)

Required the Corporation to establish procedures for determining and implementing service priorities, taking into account the relative needs of clients eligible for assistance, including people with disabilities and other individuals facing special difficulties in accessing legal services.

#### 1978 - Civil Rights Commission Act Amendments of 1978 (P.L. 95-444)

Expanded the jurisdiction of the Civil Rights Commission to include protection against discrimination on the basis of handicap.

#### 1978 - Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments (P.L. 95-602)

Established the National Institute of Handicapped Research and new programs for people with disabilities, including comprehensive service centers, independent living centers, recreation programs, and pilot programs for employment. The legislation also updated and made functional the definition of the term "developmental disability" and clarified the functions of the university-affiliated programs.

#### 1979 - Food Stamp Act of 1979 (P.L. 96-58)

Authorized food stamps for residents of community living arrangements for persons with blindness or disabilities, by redefining "eligible households" to include disabled or blind recipients of benefits under Title II or Title XVI of the Social Security Act who are



residents in a public or private nonprofit group living arrangement that is certified by the appropriate state agency or agencies regulations issued under section 1616(e) of the Social Security Act.

#### 1980 - Civil Rights of Institutionalized Persons Act (P.L. 96-247)

Authorized the U.S. Department of Justice to sue states for alleged violations of the rights of institutionalized persons, including persons in mental hospitals or facilities for people with mental retardation.

#### 1980 - Social Security Act Amendments (P.L. 96-265)

Authorized special cash payments (section 1619(a)) and continued Medicaid eligibility (section 1619(b)) for individuals who receive Supplemental Security Income (SSI) benefits but, nonetheless, engage in substantial gainful activity. The provision was made effective for three years.

#### 1980 - Federal Advisory Committee Act (P.L. 96-523)

Permitted the employment of personal assistants for federal employees with disabilities both at their regular duty station and while on travel status.

#### 1981 - Omnibus Budget Reconciliation Act (P.L. 97-35)

Consolidated six programs authorized under Title V of the Social Security Act into a single block grant authority (Maternal and Child Health) to address, among other things, the needs of children with special health care needs. In addition, the existing Title XX program was converted into a Social Services Block Grant Program.

Authorized the Secretary of Health and Human Services to grant "home and community-based" waivers to enable states to furnish personal assistance and other services to individuals who, without such services, would require institutional care as long as costs under the waiver do not exceed the cost of providing institutional care to the target population.

Limited Child Care Program to children up to age twelve, except children with disabilities, for whom no age limit was set.

#### 1981 - Small Business Act Amendments of 1981 (within the Omnibus Budget Reconciliation Act of 1981, P.L. 97-35)

Placed the Handicapped Assistance Loan Program administratively within the regular SBA loan system.

#### 1982 - Tax Equity and Fiscal Responsibility Act of 1982 (P.L. 97-248)

Permitted states to cover under their Medicaid plans home care services for certain children with disabilities, even though family's income and resources exceeded state's normal eligibility standards.

#### 1982 - Job Training Partnership Act (P.L. 97-300)

Revamped the Comprehensive Employment and Training Act (CETA). The Act emphasizes training for private sector jobs. The Act established a "State Job Training Coordinating Council" and the "Private Industry Council (PIC)".

#### 1982 - Telecommunications for the Disabled Act of 1982 (P.L. 97-410)

Required that workplace telephones used by persons with hearing aids and emergency phones be hearing-aid-compatible.

#### 1984 - Rehabilitation Act Amendments of 1984 (P.L. 98-221)

Transformed the National Council on Disability from an Advisory Board in the Department of Education into an independent federal agency.

#### 1984 - Voting Accessibility for the Elderly and Handicapped Act (P.L. 98-435)

Required that registration and polling places for federal elections be accessible to persons with disabilities.

#### 1984 - Child Abuse Amendments of 1984 (P.L. 98-457)

Required states to enact procedures or programs within child protection agencies to respond to cases in which medical treatment is withheld from disabled infants.

#### 1984 - Social Security Disability Benefits Reform Act of 1984 (P.L. 98-460)

Extended the section 1619 worker incentive program under SSI for an additional three years. The 1984 amendments also required the Secretary of HHS to publish uniform standards for SSI and SSDI disability determinations.

#### 1984 - Developmental Disabilities Act of 1984 (P.L. 98-527)

Added a statement of purpose to the Act and authorized protection and advocacy systems to have access to the records of persons with developmental disabilities residing in institutions.

#### 1985 - Consolidated Omnibus Budget Reconciliation Act of 1985 (P.L. 99-272)

Authorized states to cover case management services on less than a statewide or comparable basis to targeted groups under Medicaid; expanded the definition of "habilitation" for Home and Community-Based Waiver recipients with developmental disabilities to cover certain pre-vocational services and supported employment for previously institutionalized individuals; authorized states to cover ventilator-dependent children under the waiver program if they would otherwise require continued inpatient care.

#### 1986 - Protection and Advocacy for Mentally Ill Individuals Act of 1986 (P.L. 99-319)

Established a formula grant program operated by existing protection and advocacy systems primarily focusing on incidences of abuse and neglect of mentally ill individuals.



#### 1986 - Education of the Deaf Act of 1986 (P.L. 99-371)

Changed the name of the school from "Gallaudet College" to "Gallaudet University," and extended the statutory authority of the National Training Institute for the Deaf (a residential facility for postsecondary technical training and education for individuals who are deaf in order to prepare them for successful employment) (Title II). Established a Commission on Education of the Deaf under Title III of the Act. The Commission consists of twelve members that study the quality of infant and early childhood programs, as well as elementary, secondary, postsecondary, adult, and continuing education programs for individuals who are deaf. The Commission makes recommendations to the President and Congress for improving current programs and practices.

#### 1986 - Handicapped Children's Protection Act (P.L. 99-372)

Overtaken a Supreme Court decision and authorized courts to award reasonable attorneys fees to parents who prevail in due process proceedings and court actions under part B of the Education of the Handicapped Act.

#### 1986 - Air Carriers Access Act (P.L. 99-435)

Prohibited discrimination against persons with disabilities by air carriers and provided for enforcement by the U.S. Department of Transportation.

#### 1986 - Education of the Handicapped Act Amendments (P.L. 99-457)

Included a new grant program for states to develop an early intervention system for infants and toddlers with disabilities and their families and provide greater incentives for states to provide preschool programs for children with disabilities between the ages of three and five.

#### 1986 - Amendments to the Job Training Partnership Act (P.L. 99-496)

Required special consideration for persons with disabilities in the awarding of discretionary grants.

#### 1986 - Higher Education Act Amendments of 1986 (P.L. 99-498)

Authorized construction/renovation grants and loans to institutions of higher education. Among the purposes for which funds under this Act may be used is to bring academic facilities into compliance with the Architectural Barriers Act of 1968 and section 504 of the Rehabilitation Act of 1973.

#### 1986 - Rehabilitation Act Amendments of 1986 (P.L. 99-506)

Clarified that supported employment is a viable outcome of vocational rehabilitation and specified that states must plan for individuals making the transition from school to work.

#### 1986 - Tax Reform Act of 1986 (P.L. 99-514)

Extended "targeted jobs tax credit" through 12/31/88.

#### 1986 - Employment Opportunities for Disabled Americans Act (P.L. 99-643)

Made the section 1619(a) and 1619(b) work incentives a permanent feature of the Social Security Act. The Act also added provisions to enable individuals to move back and forth among regular SSI, section 1619(a) and section 1919(b) eligibility status.

#### 1987 - Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (P.L. 100-146)

Updated language in the legislation, strengthened the independence of the State Planning Councils, strengthened authority of protection and advocacy systems to investigate allegations of abuse and neglect, and created separate line items for core funding and training for university affiliated programs.

#### 1987 - Housing and Community Development Act of 1987 (P.L. 100-242)

Required HUD to earmark fifteen percent of section 202 funds for non-elderly persons with disabilities.

#### 1988 - Civil Rights Restoration Act (P.L. 100-259)

Amended the Rehabilitation Act of 1973's definition of an individual with a disability and defined coverage of section 504 as broad (e.g., extending to an entire university) rather than narrow (e.g., extending to just one department of the university) when federal funds are involved.

#### 1988 - Education Amendments of 1988 (P.L. 100-297)

Made a number of changes in Chapter 1, including the provisions dealing with aid to state-operated and supported schools for children with disabilities.

#### 1988 - Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360)

Clarified the circumstances under which Medicaid reimbursement would be available for services included in a child's individualized education program (IEP) or individualized family services plan (IFSP) under the Individuals with Disabilities Education Act.

#### 1988 - Hearing Aid Compatibility Act of 1988 (P.L. 100-394)

Required most telephones manufactured or imported into the United States to be compatible for use with telecoil-equipped hearing aids.

#### 1988 - Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986 (P.L. 100-403)

Authorized the Secretary of Health and Human Services to make grants to states for public and nonprofit agencies to furnish temporary, non-medical care services to children with disabilities and special health care needs.

#### 1988 - Technology-Related Assistance for Individuals with Disabilities Act (P.L. 100-407)

Provided grants to states to develop statewide assistive technology programs.

#### 1988 - Fair Housing Act Amendments (P.L. 100-430)

Added persons with disabilities as a group protected from discrimination in housing and ensured that persons with disabilities are allowed to adapt their dwelling place to meet their needs.

#### 1988 - Telecommunications Accessibility Enhancement Act of 1988 (P.L. 100-542)

Allowed the Administrator of General Services Administration (GSA) to take such actions as are necessary to assure that the federal telecommunications system is fully accessible to hearing and speech impaired individuals.

#### 1988 - Small Business Administration Reauthorization and Amendment Act of 1988 (P.L. 100-590)

Enlarged the class of organizations eligible to receive Handicapped Assistance Loans to include both public and private entities.

#### 1988 - Traffic Safety for Handicapped Individuals Act (P.L. 100-641)

Required the Department of Transportation to issue regulations establishing a uniform parking system for people with disabilities.

#### 1989 - Omnibus Budget Reconciliation Act of 1989 (P.L. 101-239)

Specified, among other things, that at least thirty percent of the Maternal and Child Health Block Grant under Title V of the Social Security Act must be used to improve services for children with special health care needs. Included a major expansion in required services under Medicaid's Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT). Required the Social Security Administration (SSA) to establish a permanent outreach program for children who are blind or otherwise disabled.

#### 1990 - Americans with Disabilities Act (ADA) (P.L. 101-336)

Guaranteed the civil rights of people with disabilities by prohibiting the discrimination against anyone who has a mental or physical disability in the area of employment, public services, transportation, public accommodations, and telecommunications.

#### 1990 - Carl D. Perkins Vocational Educational Applied Technology Amendments (P.L. 101-392)

Rewrote the vocational legislation, eliminated the ten percent earmarking for disabled youth, but included specific language to assure students with disabilities access to qualified vocational programs and supplementary services.

#### 1990 - Television Decoder Circuitry Act (P.L. 101-431)

Required closed caption circuitry (computer chip) to be part of all televisions with screens thirteen inches or larger manufactured for sale and use in the United States.

#### 1990 - Education of the Handicapped Act Amendments of 1990 (P.L. 101-476)

Stimulated the improvement of the vocational and life skills of students with disabilities to enable them to be better prepared for the transition to adult life and services.

1990 - Individuals with Disabilities Education Act Amendments (IDEA) (within the Education of the Handicapped Act Amendments of 1990, P.L. 101-476)

Renamed the Education of the Handicapped Act and reauthorized programs under the Act to improve support services to students with disabilities, especially in the areas of transition and assistive technology.

1990 - Developmental Disabilities Act Amendments of 1990 (P.L. 101-496)

Maintained and further strengthened programs authorized under the Act.

1990 - Omnibus Budget Reconciliation Act of 1990 (P.L. 101-508)

Established a limited purpose optional state coverage of community supported living arrangements services for persons with mental retardation and related conditions (authority has since expired). Authorized community supported living arrangements and stressed individualized support rather than the standardized services common to the ICF/MR program. Included a provision called the "access credit" that enables small businesses to claim credit against taxes for half of the first \$10,000 of eligible costs of complying with the ADA.

1990 - National Affordable Housing Act (P.L. 101-625)

Established a distinct statutory authority to fund supportive housing for people with disabilities, with a separate financing mechanism and selection criteria.

1991 - Individuals with Disabilities Education Act of 1991 (P.L. 102-119)

Enhanced infants and toddlers program and extended the IDEA support programs.

1991 - Civil Rights Act of 1991 (P.L. 102-166)

Reversed numerous U.S. Supreme Court decisions that restricted the protections in employment discrimination cases and authorized compensatory and punitive damages under Title V of the Rehabilitation Act of 1973 and ADA.

1991 - Intermodal Surface Transportation Efficiency Act of 1991 (P.L. 102-240)

Authorized increased set aside funds under section 16(b) of the Act to assist facilities in meeting the special transportation accessibility needs of those who are elderly or disabled.

1992 - Rehabilitation Act Amendments of 1992 (P.L. 102-569)

Included changes that increase access to state vocational rehabilitation systems for those with the most significant disabilities, enabled consumers to have greater choice and control in the rehabilitation process, and provided opportunities for career advancement.

1993 - Family and Medical Leave Act (P.L. 103-3)

Allowed workers to take up to twelve weeks of unpaid leave to care for newborn and adopted children and family members with serious health conditions or to recover from serious health conditions.

#### 1993 - National Voter Registration Act (P.L. 103-31)

Required states to liberalize their voter registration rules to allow people to register to vote by mail, when they apply for driver's licenses, or at offices that provide public assistance and programs for individuals with disabilities such as vocational rehabilitation programs.

#### 1993 - National and Community Service Trust Act of 1993 (P.L. 103-82)

Established a national service program, including tuition assistance and a living allowance for individuals age seventeen and older who volunteer part-time or full-time in community service programs.

#### 1994 - Technology-Related Assistance for Individuals with Disabilities Act Amendments (P.L. 103-218)

Reauthorized the 1988 "Tech Act," that was established to develop consumer-driven, statewide service delivery systems that increase access to assistive technology devices and services to individuals of all ages with disabilities. The 1994 amendments emphasize advocacy, systems changes activities and consumer involvement.

#### 1994 - Goals 2000: Educate America Act of 1994 (P.L. 103-227)

Provided a framework for meeting national educational goals and carrying out systemic school reform for all children, including children with disabilities.

#### 1994 - Developmental Disabilities Assistance and Bill of Rights Amendments of 1993 (P.L. 103-230)

Rewrote and updated provisions pertaining to State Planning Councils and extended and strengthened provisions pertaining to protection and advocacy systems, university affiliated programs, and programs of national significance.

#### 1994 - School-to-Work Opportunities Act of 1994 (P.L. 103-239)

Authorized funds for programs to assist students, including students with disabilities, in the transition from school to work.

#### 1994 - Improving America's Schools Act of 1994 (IASA) (P.L. 103-382)

Reauthorized the Elementary and Secondary Education Act (ESEA), which provides the framework of federal grants to states for elementary and secondary education programs. Among other provisions, the legislation amends the Individuals with Disabilities Education Act to establish a new state program supporting statewide systems of support for families of children with disabilities.

#### 1995 - Child Abuse Prevention and Treatment Act (CAPTA) Amendments of 1995 (P.L. 104-235)

Included new family resource and support program that supports state efforts to develop, operate, expand and enhance a network of community-based, prevention-focused, family resource and support programs which would be equipped to address, among other things, the additional family support needs of families with children with disabilities.

#### 1996 - Telecommunications Act of 1996 (P.L. 104-104)

Required telecommunications manufacturers and service providers to ensure that equipment is designed, developed, and fabricated to be accessible to and usable by individuals with disabilities, if readily achievable.

#### 1996 - Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1996 (P.L. 104-183)

Extended authority to fund Developmental Disabilities Councils, Protection and Advocacy Systems, University Affiliated Programs, and Projects of National Significance.

#### 1996 - Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191)

Improved access to health care for twenty-five million Americans by guaranteeing that private health insurance is available, portable, and renewable; limiting pre-existing condition exclusions; and increasing the purchasing clout of individuals and small employers through incentives to form private, voluntary coalitions to negotiate with providers and health plans.

#### 1996 - Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193)

Provided a new, more restrictive definition of disability for children under the Supplemental Security Income program (SSI), focusing on functional limitations, mandating changes to the evaluation process for claims and continuing disability reviews, and requiring redeterminations to be performed before a child turns eighteen.

#### 1996 - Mental Health Parity Act of 1996 (P.L. 104-204) (provisions implementing Act added in P.L. 105-34)

Included a provision that prohibits insurance companies from having lower lifetime caps for treatment of mental illness compared with treatment of other medical conditions.

#### 1997 - Individuals with Disabilities Education Act Amendments of 1997 (P.L. 105-17)

Included the first major changes to Part B since enactment in 1975, extended the early intervention program, and included a significant streamlining of the discretionary programs.

#### 1997 - Balanced Budget Act of 1997 (P.L. 105-33)

Established the State Children's Health Insurance Program (SCHIP) to expand health insurance coverage for low-income children not covered by Medicaid;  
Authorized the Social Security Administration to make redeterminations of childhood SSI recipients who attain age eighteen using adult disability criteria one year after they turn eighteen;

Provided that states must continue Medicaid coverage for disabled children who were receiving SSI benefits as of August 22, 1996 and would have been eligible except their eligibility terminated because they did not meet the new SSI childhood disability criteria;



Permitted states to allow workers with disabilities whose family income is less than 250% of poverty to buy into Medicaid (and pay premiums based on sliding scale of income);

Eliminated the requirement of prior institutionalization with respect to habilitation services provided under the Medicaid Home and Community-Based Waiver;  
Provided that “qualified alien” noncitizens lawfully residing in the United States who received SSI on August 22, 1996, would remain eligible for SSI—i.e., eligibility “grandfathered”;

Provided that “qualified aliens” lawfully residing in the United States on August 22, 1996 would be eligible for SSI if they meet the SSI definition of disability or blindness;  
Directed the Secretary in consultation with specified organizations to conduct a study of Medicaid’s EPSDT program;

Permitted states to mandate adults (including adults with disabilities) into Medicaid managed care by an amendment to state Medicaid plan and not by having a waiver approved. Exempts SSI eligible kids, certain foster care and adopted kids, and certain Native Americans; and

Directed the Secretary to undertake a study of any special challenges of serving children with special health care needs and chronic conditions in Medicaid managed care.

#### 1998 – Workforce Investment Act of 1998 (P.L. 105-220)

Consolidated many of the federal job training programs and provided workforce investment activities through statewide and local workforce investment systems. The law also reauthorized the Rehabilitation Act of 1973 by providing greater linkages with the generic workforce investment systems, increased consumer choice and involvement, and greater accountability (outcome measures).

#### 1998 - Assistive Technology Act of 1998 (P.L. 105-394)

Reauthorized and extended the programs formerly authorized under the Technology-Related Assistance for Individuals with Disabilities Act, while limiting to thirteen years a state’s eligibility for a systems change grant.

#### 1998 - Crime Victims and Disabilities Awareness Act (P.L. 105-301)

Directed the Attorney General to conduct a study to examine the nature and extent of crimes committed against people with disabilities.

#### 1999 - Ticket to Work and Work Incentives Improvement Act (P.L. 106-170)

Provided health care and employment preparation and placement services to individuals with disabilities that will enable those individuals to do the following:

- Reduce their dependency on cash benefit programs;

- Encourage states to adopt the option of allowing individuals with disabilities to purchase Medicaid coverage that is necessary to enable

such individuals to maintain employment;

Provide individuals with disabilities the option of maintaining Medicare coverage while working; and

Establish a return to work ticket program that will allow individuals with disabilities to seek the services necessary to obtain and retain employment and reduce their dependency on cash benefit programs.



### APPENDIX 3

## WEBSITES FOR FEDERAL DISABILITY-RELATED LEGISLATION, REGULATIONS, AND COURT CASES:

**Access Board:** Provides information relating to accessibility for people with disabilities. Updated Monthly.  
URL: <http://www.access-board.gov>

**ADA Technical Assistance Program (ADATA):** A comprehensive resource for information on the Americans with Disabilities Act. Updated weekly.  
URL: <http://www.adata.org>

**Disability and Business Technical Assistance Centers (DBTACs):** The ten regional centers provide information, training, and technical assistance to employers, people with disabilities, and other entities with responsibilities under the ADA. Updated weekly to monthly.  
URL: <http://www.adata.org/text-dbtac.html>

**Equal Employment Opportunity Commission (EEOC) Facts Page:** Provides information and technical assistance relating to employment and disabilities. Updated weekly to monthly.  
URL: <http://www.eeoc.gov>

**Federal Communications Commission's Disabilities Issues Task Force Home Page:** Telecommunications accessibility information line. Updated monthly.  
URL: <http://www.fcc.gov/cib/dro>

**Health Care Finance Administration (HCFA) of the Department of Health and Human Services:** Federal agency that administers the Medicare, Medicaid, and Child Health Insurance Programs. Updated weekly.  
URL: <http://www.hcfa.gov>

**The Department of Health and Human Services (DHHS), Office of Civil Rights:** Promotes and ensures that people have equal access to and opportunity to participate in and receive services in all HHS programs without facing unlawful discrimination. Updated weekly to monthly.  
URL: <http://ocr.hhs.gov>

**Health Resources and Services Administration (HRSA) of the Department of Health and Human Services:** An agency that helps provide health resources for medically underserved populations. Updated weekly to monthly.  
URL: <http://www.hrsa.dhhs.gov>

**Housing and Urban Development (HUD), Department of:** Provides information and technical assistance relating to housing and disabilities. Updated weekly to monthly.  
URL: <http://www.hud.gov/disabled.html>

**Job Accommodation Network (JAN):** JAN is an information network and consulting resource that enables qualified workers with disabilities to be hired or retained. It brings together information from many sources about practical ways of making accommodations for employees and applicants with disabilities. Updated weekly to monthly.  
URL: <http://janweb.icdi.wvu.edu>

**Department of Justice (ADA Home Page) (DOJ):** Americans with Disabilities Act information and technical assistance line. Updated weekly.  
URL: <http://www.usdoj.gov/crt/ada/adahom1.htm>

**The Department of Labor (DOL):** Provides information and technical assistance relating to the American workforce and disabilities. Updated weekly to monthly.  
URL: <http://www.dol.gov>

**National Council on Disability (NCD):** Promotes policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature of severity of the disability, and empowers individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society. Updated monthly.  
URL: <http://www.ncd.gov>

**National Institute on Disability and Rehabilitation Research (NIDRR) of the Department of Education:** Provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. Updated weekly to monthly.  
URL: <http://www.ed.gov/offices/OSERS/NIDRR>

**Office of Special Education and Rehabilitative Services (OSERS) of the Department of Education:** Administers programs and projects relating to the provision of a free appropriate public education to all children, youth and adults with disabilities, from birth through age twenty-one. Updated weekly to monthly.  
URL: <http://www.ed.gov/offices/OSERS>

**Presidential Task Force on Employment of Adults with Disabilities (PTFEAD) of the Department of Labor:** The task force evaluates existing Federal programs to determine what changes, modifications, and innovations may be necessary to remove barriers to employment opportunities faced by adults with disabilities. Updated weekly to monthly.  
URL: [http://www.2dol.gov/dol/\\_sec/public/programs/ptfead/main.htm](http://www.2dol.gov/dol/_sec/public/programs/ptfead/main.htm)

**Rehabilitation Services Administration (RSA) of the Department of Education:**

Lists overseas programs that enable individuals with physical or mental disabilities to obtain employment through such supports as counseling, medical care, job training, and other individualized services. Updated weekly to monthly.

URL: <http://www.ed.gov/offices/OSERS/RSA>

**Social Security Administration (SSA) - Disability Information Page:** Provides information and technical assistance relating to social security and disabilities. Updated weekly to monthly.

URL: <http://www.ssa.gov/odhome/odhome.htm>

**Thomas:** An on-line site that provides legislative information: Text of bills, committee reports, historical documents, links to the U.S. Senate, House of Representatives, Executive, Judicial, and State/Local governments. Updated daily.

URL: <http://thomas.loc.gov>

**Transportation, Department of:** Provides information and technical assistance relating transportation and disabilities. Updated weekly to monthly.

URL: <http://www.fta.dot.gov>

**“HOT” LEGAL SITES FOR DISABILITY COURT CASES:**

**Findlaw:** On-line access to legal resources. This site is very user friendly. Updated weekly.

URL: <http://www.findlaw.com>

**Legal Information Institute (LII):** On-line access to legal documents. Excellent resource. Updated weekly to monthly.

URL: <http://www.law.cornell.edu/lii.html>

## APPENDIX 4

### GLOSSARY OF ACRONYMS:

**ADA** is an acronym for the Americans with Disabilities Act. The ADA is an omnibus civil rights statute providing a clear and comprehensive national mandate for the elimination of discrimination against persons with disabilities. It provides clear, strong, consistent, and enforceable standards addressing discrimination against such individuals. Areas covered by the ADA include employment (Title I), public services and transportation (Title II), public accommodations (Title III), and telecommunications-relay systems for persons who have communication impairments (Title IV).

**CHIP** is an acronym for Children's Health Insurance Program. CHIP is codified in Title XXI of the Social Security Act. CHIP entitles states to \$40 billion over the next ten years to provide health insurance for low-income children who do not qualify for Medicaid, including children with disabilities.

**EPSDT** is an acronym for Early and Periodic Screening, Diagnosis, and Treatment. EPSDT is a mandatory service under the Medicaid program. Under EPSDT, children are screened for health deficiencies, diagnosed, and then treated to the extent that a service is medically necessary.

**FAPE** is an acronym for "free appropriate public education" under the Individuals with Disabilities Education Act. FAPE means special education and related services provided without charge in conformity with an individualized education program.

**IDEA** is an acronym for the Individuals with Disabilities Education Act. The purposes of this Act are to:

- Ensure that all children with disabilities have available to them a free and appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living. It also ensures that the rights of children with disabilities and parents of such children are protected, and it assists states and local educational agencies to provide for the education of such children (Part B of the IDEA);
- Assist states in implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities and their families (Part C—formerly Part H—of the IDEA);
- Ensure that educators and parents have the necessary tools to improve educational results for children with disabilities by supporting systemic change activities, coordinated research and personnel preparation, coordinated technical

assistance, dissemination, and support, and technology development and media services (Part D of the IDEA).

**IEP** is an acronym for Individualized Education Program. Every child with a disability is entitled to an IEP under the IDEA. An IEP is a written statement that includes a statement of the child's present level of educational performance; measurable annual goals, including benchmarks or short-term objectives; a statement of special education, related and supplementary aids and services provided to the child; a statement of needed transition services; and periodic report cards.

**NIDRR** is an acronym for The National Institute on Disability and Rehabilitation Research in the U.S. Department of Education. NIDRR provides research, demonstration projects, training, and related activities to maximize the full inclusion, integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages.

**SECTION 504** is an acronym for section 504 of the Rehabilitation Act of 1973. Section 504 prohibits discrimination on the basis of disability by recipients of federal financial assistance.

**SSDI** is an acronym for the Social Security Disability Income program, established under Title II of the Social Security Act. SSDI provides federal disability insurance benefits for workers who have contributed to the Social Security Trust Fund and become disabled or blind before retirement age. Spouses with disabilities and dependent children of fully insured workers (often referred to as the primary beneficiary) also are eligible for disability benefits upon the retirement, disability, or death of the primary beneficiary.

**SSI** is an acronym for Supplemental Security Income program established under Title XVI of the Social Security Act. SSI is a federally administered cash assistance program for individuals who are aged, blind, or disabled and meet a financial needs test (income and resource limitations).

***The Emerging Disability Policy Framework:  
A Guide for Developing Public Policy  
For Persons with Disabilities***

**Iowa Law Review August 2000, Volume 85/No. 5**

<http://www.childrenshospital.org/ici>  
<http://www.comop.org>  
<http://www.uiowa.edu/~lhpdc/work/index.html>

Prepared By: Robert Silverstein

**I. Introduction**

- How do policy makers view/treat people with disabilities?
- The disability policy framework can be used:
  - As a lens, guidepost, benchmark to assess social policy from the viewpoint of persons with disabilities
  - To look at how persons with disabilities and their families are addressed in public policy
  - As a measure for expanding and improving public policy for persons with disabilities
- The disability policy framework can be used to look at all types of public policy such as
  - Generic programs and policies that include people with and without disabilities
  - Disability-specific programs and policies focused solely on persons with disabilities and their families

**II. Old Versus New Paradigm of Disability Policy**

**A. Old Paradigm**

1. View/treat people with disabilities as “defective” and in need of “fixing”
2. Disability connotes “unable” and “incapable”
3. Approach: out of sight, out of mind
4. Examples
  - States laws which stated that persons with specified disabilities are “unfit for citizenship”
  - States laws that required sterilization of the “feebleminded” with the aim of “extinguishing their race”
  - States laws that permitted school districts to exclude children with disabilities when school officials determined that it was too much of a burden or “inexpedient” to serve

them or because they produced a “nauseating” effect on others

- State laws that required persons with disabilities to be placed in institutions because they were a “menace to society”

#### B. New paradigm

1. Disability is a physical or mental condition that affects a person’s ability to function
2. Focus on how a person with a disability interacts with the world
3. New core precept—disability is a natural part of the human experience that in no way diminishes a person’s right to fully participate in all aspects of American life
4. Goal of public policy is to determine how society can “fix” the environment to provide effective and meaningful opportunities.

### III. **Goals, Core Policies, Methods of Administration and Support Program Constituting the Disability Policy Framework**

#### A. Goals of Disability Policy

1. Equality of Opportunity
2. Full Participation
3. Independent Living
4. Economic Self-sufficiency

#### B. Core Policies

##### 1. Equality of Opportunity

- Individualization (treat people on the basis of facts and objective evidence, not generalizations, stereotypes, or fear ignorance and prejudice)
- Genuine, effective and meaningful opportunity (provide reasonable accommodations, make programs accessible, and make reasonable modifications to policies)
- Inclusion and integration (guarantee contact with nondisabled persons, avoid unnecessary and unfair separation and segregation)

##### 2. Full Participation

- Involvement in decision-making by persons with disabilities and their families at the individual and systems levels
- Ensure informed choice
- Provide for self-determination and empowerment
- Recognize self-advocacy

### 3. Independent Living

- Recognize independent living as a legitimate outcome of public policy
- Provide for independent living skills development
- Provide for long-term services and supports, including personal assistant services and assistive technology devices and services
- Provide cash assistance

### 4. Economic Self-sufficiency

- Recognize economic self-sufficiency as a legitimate outcome of public policy
- Support systems providing employment-related services
- Provide cash assistance with work incentives and other forms of assistance
- Devise a tax policy providing incentives to employers and employees

## C. Methods of Administration

1. Methods of Administration, In General
2. State and Local Plans, Applications, and Waivers
3. Monitoring and Enforcement by Government Agencies
4. Procedural Safeguards
5. Accountability for Results (Outcome Measures)
6. Representation at the Individual and Systems Level
7. Single Line of Responsibility/Coordination and Collaboration Among Agencies
8. Service Coordination
9. Financing Service Delivery
10. Privacy, Confidentiality, Access to Records, and Informed Consent
11. Comprehensive System of Personnel Development and Personnel Standards
12. Racial, Ethnic, and Linguistic Diversity
13. Fiscal Provisions
14. Financial Management and Reporting Provisions

## D. Program Supports

1. Systems Change Initiatives
2. Technical Assistance
3. Research



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*Revised: October 20, 2000*

## ***Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy***

By: Robert Silverstein

Bobby Silverstein, Director of the Center for the Study and Advancement of Disability Policy (former Staff Director and Chief Counsel of the U. S. Senate Subcommittee on Disability Policy chaired by Tom Harkin) recently completed an article published in the Iowa Law Review (August 2000, Vol. 85/No. 5) entitled *Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy*.

The Article describes the precept, goals, and core policies of our nation's laws relating to people with disabilities. The purpose of the Article is to provide a framework that can be used as a lens or guidepost to design, implement, and evaluate generic, as well as disability-specific, public policies and programs to ensure meaningful inclusion of people with disabilities in mainstream society.

Appendix 1 to the Article is a self-contained document, which provides an overview of the Emerging Disability Policy Framework. The overview is written in a narrative outline format and can serve as a handout for training purposes.

Appendix 2 describes major disability-related legislation enacted between 1956 – 2000.

The Article's intended audiences include federal, state and local policymakers, persons with disabilities, their families and advocates, researchers, service providers, and university professors teaching courses that include disability policy.

The Article and the overview are available on-line through websites operated by two Rehabilitation Research and Training Centers (RRTC) funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education.

- <http://www.comop.org> (RRTC on Workforce Investment and Employment Policy for Persons with Disabilities (No. H133B980042) operated by Community Options, Inc.
- <http://www.childrenshospital.org/ici> (RRTC on State Systems and Employment (No. H133B30067) operated by the Institute for Community Inclusion

In addition, the Article may be found at a website supported by a grant from the Robert Wood Johnson Foundation.

<http://www.uiowa.edu/~lhpdc/work/index.html> (Comprehensive, Person-Centered State Work Incentive Initiatives: A Resource Center for Developing & Implementing Medicaid Buy In Programs & Related Employment Initiatives for Persons with Disabilities)

# Youth Leadership Forum

# **HOW TO CONDUCT A CALIFORNIA MODEL YOUTH LEADERSHIP FORUM FOR STUDENTS WITH DISABILITIES (YLF)**

**YLF**

## **A Resource Manual**

**presented by the**

**California Governor's Committee**

**for Employment of Disabled Persons  
in association with the**

**State Relations Subcommittee**

**of the**

**President's Committee on Employment**

**of People With Disabilities**

**1998**

# **YOUTH LEADERSHIP FORUM** **For Students With Disabilities**

CALIFORNIA GOVERNOR'S COMMITTEE FOR  
EMPLOYMENT OF DISABLED PERSONS

*August 3 - August 7, 1997*

PARTNERS IN LEARNING  
PATHWAYS FOR LEADING

## **Program Schedule and Student Delegate Workbook**

**Name:** \_\_\_\_\_

## **PURPOSE OF THE YOUTH LEADERSHIP FORUM: *WHAT WE WILL ACCOMPLISH THIS WEEK***

We will share many experiences this week which explore the principles of leadership. Our activities will help student delegates to develop an appreciation of the past, an understanding of the present and a belief in the future.

### **WHAT IS "LEADERSHIP"?**

Leadership is the ability to analyze one's own strengths and weaknesses, set personal and vocational goals and have the self-esteem to carry them out. It includes the ability to identify community resources and use them, not only to live independently, but also to establish support networks to participate in community life and affect positive, social change.

### **HOW WILL WE LEARN ABOUT "LEADERSHIP" DURING THE FORUM?**

We will learn about the principles of leadership through experiences presented in the following modules or sections: "Principles Of Leadership", "The Experience of Disability," "Living On My Own and Reaching My Career Goals," "Leading In My Community" and "Technology and Resources to Reach My Goals."

### **WHAT ARE THE FORUM'S GOALS AND HOW WILL WE REACH THEM?**

During the Forum, we will:

#### **GOAL #1 "Develop an Appreciation of the Past and Present. . . ."**

- Learn about the history of disability as a culture

#### **GOAL #2 "Develop an Understanding of the Present. . . ."**

- Explore the basic principles that make a leader
- Meet with successful professionals who are people with disabilities
- Participate in new experiences to help us reach our goals

#### **GOAL #3 "Develop A Belief in the Future. . . ."**

- Learn about career and education options
- Learn about community resources to reach our goals

- Learn ways to make positive contributions to the community
- Develop a "Personal Leadership Plan" and use it when we return home to help us reach our goals

## **PRINCIPLES OF LEADERSHIP**

The experiences of the forum focus on exploring and developing the basic principles of leadership. Individuals who are leaders typically share the following personal characteristics:

- Vision (ability to set and implement goals)
- Awareness of Own Strengths and Weaknesses (and their personal uniqueness)
- Ability to Motivate Others
- Integrity and Honesty
- Trust
- Effective Decision Making Ability
- Enthusiasm
- Critical Thinking
- Support for Teamwork
- Understanding of Conflict Resolution
- Social Responsibility (Genuine concern for others)
- Support for Continuous Improvement and Change
- Willingness to Share Power
- Determination and Perseverance
- Demonstration of Personal Values Through Behavior
- Respect For Diversity and Individual Differences
- Belief in a Higher Purpose—To Serve Others



## RULES AND GUIDELINES FOR STUDENT DELEGATES

***THESE RULES AND GUIDELINES HAVE BEEN DEVELOPED TO PROMOTE A POSITIVE LEARNING ENVIRONMENT FOR ALL PARTICIPANTS.***

### **ALL DELEGATES MUST:**

- Maintain a respectful attitude toward peers, facilitators and conference staff.
- Respect the facilities, including maintaining the condition of dormitory rooms and all other areas. Participants will have to pay for property damage they cause and for lost room keys or towels.
- Interact with as many students as possible during the forum.
- Be punctual for all meetings, activities, and transportation.
- Be at designated places at all times. ***Attendance at all sessions is mandatory including ALL meals and social functions.***
- Stay with your assigned group at all times. Do not wander off alone. (Supervision is mandatory for all participants.)
- Be out of dorms by 7:30 a.m. at the latest. (Wake-up call is at 6:30 a.m. and breakfast is served from 7:00 - 8:00 a.m.)
- Be in your room each night for lights out at 10:00 p.m.

### **ADDITIONAL REQUIREMENTS:**

- No stereos, radios or electronic games permitted during forum sessions.
- After arrival on campus, no student delegates are allowed to drive or ride in personal vehicles belonging to student delegates (until departure).
- All other residence halls are off limits to delegates except for our headquarters, Desmond Residence Hall.
- If you have any problems or questions, please contact one of your group co-counselors. When not in assigned groups, males and females are restricted to their own assigned rooms at all times. No coed visitation is allowed in guestrooms.

- Use of the swimming pool is prohibited by CSU, Sacramento, and other facilities are restricted to scheduled and supervised periods of time.
- Smoking, possession or use of illegal chemicals or alcohol are strictly prohibited. (Possession and use of prescription or other approved medications is permitted only with written permission/instruction slip on file from parent/guardian physician. Medication will be dispensed by nursing staff in first aid station.)
- \* **Please note: Any serious violations of these rules will result in students being sent home immediately at parents'/guardians' expense.**

**REMEMBER THAT YOU HAVE BEEN SELECTED TO ATTEND THIS FORUM BECAUSE OF YOUR LEADERSHIP POTENTIAL. ENJOY YOURSELF AND RECOGNIZE THE RESPONSIBILITY YOU HAVE WITH THIS HONOR.**

## **SECTION I:**

# **DAILY SCHEDULE**

WEEK-AT-A-GLANCE (August 3 – August 7, 1997)						
Time	Sunday 8/3	Monday 8/4	Tuesday 8/5	Wednesday 8/6	Thursday 8/7	Time
7 AM		Breakfast Served	Breakfast Served	Breakfast Served	Breakfast Served	7 AM
8:00			Small Groups (8:15-9:30) Prepare for Large Groups	Travel to State Capital (Buses depart at 8:30)	Small Groups: Complete Personal Leadership Plan	8:00
8:30				Photo and Press Session		8:30
9:00				Large Group Session IV: Meeting in Governor's Office		9:00
9:30				State Capitol Tour in Small Groups (11:00-12:00)		9:30
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10:00						10:00

## **PROGRAM SCHEDULE**

**SUNDAY, AUGUST 3, 1997**

**SEGMENT 1- 3:00 p.m. - STAFF CHECK-IN**

**SEGMENT 2- 4:30 p.m. - ORIENTATION BEGINS (ALL STAFF)  
(continues through dinner until 7:30 p.m.)**

**Format:** Individuals and Large Group (staff only)

**LOCATION:** Office, Desmond Residence Hall (Check-in) Meeting Room,  
Desmond Hall (Orientation)

**ACTIVITY:** Staff check-in to residence hall and orientation

**PURPOSE:** After check-in, orientation meeting of all staff; overall orientation,  
review of program and schedule, plus opportunity to share updates  
and make announcements.

**SEGMENT 3- 6:00 p.m. - DINNER (STAFF ONLY)**

**FORMAT:** Large Group (staff only)

**LOCATION:** Desmond Residence Hall

**ACTIVITY:** Dinner (with orientation continuing until 7:30 p.m.)

## ***MONDAY, AUGUST 4, 1997***

**SEGMENT 4- (NOTE: Breakfast served 7:00-8:00 a.m. for staff only)  
8:30-11:30- SMALL GROUP STAFF MEETINGS  
(AND LUNCH 12:00 - 1:00 p.m.)**

**FORMAT:** Small Groups (staff only)

**LOCATION:** Desmond Residence Hall  
(assigned small group meeting rooms)

**ACTIVITY:** Staff will complete planning for small group activities and review  
program (followed by lunch for staff only in Residence Dining Hall)

***MONDAY, AUGUST 4, 1997 (continued)***

**SEGMENT 5 - 1:15 - 3:00 p.m. - STUDENT CHECK-IN**

**FORMAT:** Individuals

**LOCATION:** Office and Recreation Room Desmond Residence Hall

**ACTIVITY:** Delegates check-in; Individual Activities; Receive Small Group Assignments  
(Program Assistants and Peer Counselors Coordinate)

**PURPOSE:** Informal time while delegates arrive

**SEGMENT 6- 3:00-4:00 p.m. - STUDENT ORIENTATION**

**FORMAT:** Small Groups

**LOCATION:** Small Group meeting rooms, Desmond Residence Hall

**ACTIVITY:** Small group orientation of students, introduction of students and Co-counselors

**PURPOSE:** Co-counselors welcome individuals assigned to their groups and begin to get to know each other; orientation regarding expectations, guidelines; select group name for each small group; review program schedule, with emphasis on "**Personal Leadership Plan**"; Complete Session Work Sheet #1 - "The Ungame"

**SEGMENT 7- 4:15 - 4:45 p.m. - WELCOME - LARGE GROUP (SESSION I)**

**FORMAT:** Large Group

**LOCATION:** Desmond Residence Hall Recreation Room

**ACTIVITY:** Introductions and overview of program by YLF Chair, Paul K. Miller and Governor's Committee Executive Director, Catherine Kelly Baird. Review of schedule by YLF Alumni/Staff Nam Dang and Robyn Ward. Program Assistants demonstrate process for introductions of speakers.

**PURPOSE:** Welcome delegates and review plans for the forum.

***MONDAY, AUGUST 4, 1997 (continued)***

**SEGMENT 8- 5:00-6:00 p.m. - DINNER SERVED**

**FORMAT:** Small Groups

**LOCATION:** Residence Dining Hall

**ACTIVITY:** Dinner and Discussion

(Student delegates meet outside Desmond Hall at 4:55; go together in assigned small groups with Co-Counselors, assisted by Program Assistants and Peer Counselors; informal interaction in small groups.)

**Forum Module 1 - Principles of Leadership and**  
**Forum Module 2 - The Experience of Disability**

**SEGMENT 9- 6:30 - 7:30 p.m. LARGE GROUP (SESSION II)**

**FORMAT:** Large Group

**LOCATION:** Desmond Residence Hall, Recreation Room

**ACTIVITY:** Presentation on "What Is Leadership" by Dana La Mon, Administrative Law Judge and presentation on "Understanding the Experience of Disability In A Historical Perspective" by Dr. Paul Longmore, Professor, San Francisco State University, and Sarah Triano, YLF Alumni/Staff and graduate student, San Francisco State University.

**SEGMENT 10- 7:45-8:30 p.m. SMALL GROUPS**

**FORMAT:** Small Groups

**LOCATION:** Desmond Residence Hall, Small Meeting Rooms

**ACTIVITY:** Co-counselors facilitate small group discussions on what leadership is and Complete Session Work Sheet #2 - Leaders and Complete Session Work Sheet #3 "Assets and Strengths;" review **"Personal Leadership Plan"** and continue earlier discussion on schedule and expectations for the forum.

***MONDAY, AUGUST 4, 1997 (continued)***

**SEGMENT 11- 8:30-9:00 p.m. INDIVIDUAL PERSONAL TIME  
(STUDENTS)**

**FORMAT:** Individuals (Students only)  
Staff Meeting (Staff only)

**LOCATION:** Desmond Residence Hall (Staff Meeting in Television Room)

**ACTIVITY:** Individual personal time (students) staff meeting (staff only)

**LIGHTS OUT** 10:00 p.m.!

***TUESDAY, AUGUST 5, 1997***

**SEGMENT 12- 7:00-8:00 a.m. BREAKFAST SERVED**

**FORMAT:** Individuals

**LOCATION:** Residence Dining Hall

**ACTIVITY:** BREAKFAST

**SEGMENT 13- 8:15-9:45 a.m. - SMALL GROUPS**

**FORMAT:** Small Groups

**LOCATION:** Desmond Residence Hall, Small Meeting Rooms

**ACTIVITY:** Overview discussion of upcoming presentations; Small groups prepare questions for presentations as follows: Small Group #1 prepares questions for Large Group Session 11 on "Disability As a Culture," Small Group #2 prepares questions for Large Group Session III on "Technology and Resources to Reach My Goals," Small Group # 3 prepares questions for Large Group Session IV on "Reaching My Career Goals Through Education and Training," Small Group #4 prepares for Large Group Session V "Leading In My Community, Small Group #5 for Large Group Session VI - Mentors' Luncheon and Small Group #6 for Large Group Session VII-Closing Session.



***TUESDAY, AUGUST 5, 1997 (continued)***

**SEGMENT 14- 10:00a.m. - 11:50 a.m. - LARGE GROUP (SESSION III)  
TECHNOLOGY DEMONSTRATION (Introduction by  
Small Group #2)**

**FORMAT:** Large group

**LOCATION:** Begin in Desmond Hall Recreation Room; after overview, and presentation of "Resource Guide," go in small groups to exhibits inside and outside of Desmond Hall to participate in technology demonstrations and presentations.

**ACTIVITY:** A special demonstration on "Technology and Resources to Reach My Goals"

**Presenters:** Mark Wellman, nationally renowned athlete, will present an overview of this segment and introduce the "Resource Guide." Exhibitors include: Elena Negrete (Tri Visual Services); Michael Moesher (EXAC Microservices); Kent Gregory (California Assistive Technology System [CATS]); Barbara Thieman, Disabled Services (Pacific Bell); Kathleen Hicks, Personnel Analyst (Dept. of Human Resources); Jeff Symons, Rehabilitation Engineer; Lewis Whittaker, (Employment Development Department).

**SEGMENT 15- 12:00-1:00 p.m. - LUNCH SERVED**

**FORMAT:** Small Groups

**LOCATION:** Residence Dining Hall

**ACTIVITY:** Lunch with small groups

**SEGMENT 16- 1:15 - 2:00 p.m. - SMALL GROUPS**

**FORMAT:** Small Groups

**LOCATION:** Desmond Residence Hall, Meeting Rooms

**ACTIVITY:** Discussion of issues from Large Group Presentations; Complete Session Work Sheet #4 - "Independent Living Assessment," Session Work Sheet #5, "Decisions, Decisions," and Session Work Sheet #6, "Finding a Purpose and Making a Difference."

***TUESDAY, AUGUST 5, 1997 (continued)***

**Forum Module 3 - Living On My Own and Reaching My Career Goals**

**SEGMENT 17- 2:15-3:15 p.m. - LARGE GROUP (SESSION IV)  
(Introductions and Follow-Up questions by Small Group #3)**

**FORMAT:** Large Group

**LOCATION:** Desmond Residence Hall, Recreation Room

**ACTIVITY:** Panel Discussion on "Living On My Own and Reaching My Career Goals."

**Presenters:** Susan Portugal, Vice President, Bank of America; R. David Smith, Actor and Stunt person; Frank Johnson, Former Professional Football Player and Janay Lawrence, Teacher.

**SEGMENT 18- 3:30-4:00 p.m. - SMALL GROUPS**

**FORMAT:** Small Groups

**LOCATION:** Desmond Residence Hall, Meeting Rooms

**ACTIVITY:** Discussion of issues from Large Group Presentations; Complete Session Work Sheet #7 - "Barriers to Assertiveness," prepare for next day's "Mentors' Luncheon," Small Group #4 prepares questions for Segment 26 in Governor's Office.

**SEGMENT 19- 4:00-5:00 p.m. - PREPARE FOR TALENT SHOW**

**FORMAT:** Individuals and Groups

**LOCATION:** Desmond Residence Hall

**ACTIVITY:** Prepare acts for talent show

**SEGMENT 20- 5:00-6:00 p.m. - DINNER SERVED - BARBECUE  
(and continue preparation for Talent Show after dinner)**

**FORMAT:** Large Group

***TUESDAY, AUGUST 5, 1997 (continued)***

LOCATION: Patio outside of Residence Dining Hall (Do not go inside Dining Hall!)

ACTIVITY: Barbecue Dinner; after dinner, continue preparation for Talent Show

**SEGMENT 21- 7:00-9:00 p.m. - TALENT SHOW**

FORMAT: Large Group

LOCATION: Desmond Residence Hall

ACTIVITY: Talent show by delegates and staff

Presenters: All YLF delegates

**SEGMENT 22- 9:00-10:00 p.m. - INDIVIDUAL AND GROUP**

FORMAT: Large Group

LOCATION: Desmond Residence Hall, Recreation Room

ACTIVITY: Personal time (students) and Staff Meeting (all staff except Program Assistants)

**LIGHTS OUT: 10:00 P.M.**

**WEDNESDAY, AUGUST 6, 1997**

**\*NOTE: YLF T-SHIRT REQUIRED UNTIL RETURN  
TO CSUS CAMPUS IN AFTERNOON**

**SEGMENT 23- 7:00-7:45 a.m. - BREAKFAST SERVED**

**FORMAT: Individuals**

**LOCATION: Residence Dining Hall**

**ACTIVITY: Breakfast**

**SEGMENT 24- 8:00-9:00 a.m. - TRAVEL TO CAPITOL**

**FORMAT: Large Group**

**LOCATION: Meet outside Desmond Residence Hall**

**ACTIVITY: Travel to State Capitol (Buses begin boarding promptly at 7:45 and  
leave exactly at 8:30 a.m.!!!!)**

**SEGMENT 25- 9:00-9:45 a.m. - GROUP PHOTO SESSION**

**FORMAT: Large group**

**LOCATION: Outside State Capitol (West steps)**

**ACTIVITY: Group picture session and meet with press**

**Forum Module 5 - Leading In My Community**

**10:00-11:00 a.m. - MEETING IN GOVERNOR'S OFFICE (Introductions  
and Follow-up Questions by Small Group #4)**

**FORMAT: Large group (Session V)**

**LOCATION: State Capitol, Governor's Council Room**

**ACTIVITY: Welcome from State dignitaries and Governor's Office.  
Presentations on "Leading in My Community."**

**Presenters: Governor Pete Wilson (invited); Brenda Premo, Director, State  
Department of Rehabilitation and Sandra R. Smoley, Secretary,  
Health and Welfare Agency.**

**WEDNESDAY, AUGUST 6, 1997 (continued)**

**SEGMENT 27- 11:00 a.m. -12:00 noon - STATE CAPITOL TOUR**

**FORMAT:** Small Groups

**LOCATION:** California State Capitol

**ACTIVITY:** Brief tour of State Capitol (in regular assigned small groups)

**SEGMENT 28- 12:00-12:30 p.m. - WALK TO HYATT REGENCY**

**FORMAT:** Small Groups

**LOCATION:** State Capitol

**ACTIVITY:** Walk to Hyatt Regency

**SEGMENT 29- 12:30-2:00 p.m. - LUNCHEON PROGRAM  
(Introductions by Small Group #5)**

12:30 Interaction with mentors while eating lunch

1:15 Guest presenters

2:00 Program Ends

**FORMAT:** Large Group (Session VI)

**LOCATION:** Hyatt Regency Hotel (1st floor Ballroom)  
1209 L Street (across from State Capitol)

**ACTIVITY:** Mentors' Luncheon  
(Please note: At this luncheon, delegates have an opportunity to meet and talk with successful adults, most of whom have disabilities. Each table has an assigned "Facilitator" to encourage information sharing and discussion.)

**Presenters:** Welcome from YLF Chair, Paul K. Miller and Governor's Committee Executive Director, Catherine Kelly Baird. Introduction of YLF sponsors and partners. Presentations by actor-comedian Alex Valdez and YLF Alumni Wil Arnold and Eida Fernandez.

**Special**

**Guests:** Individuals with disabilities who lead through example

***(Reminder - At 2:30, buses load to return to CSUS Campus)***

***WEDNESDAY, AUGUST 6, 1997 (continued)***

**SEGMENT 30- 2:45 p.m. - RETURN TO CSUS CAMPUS**

**FORMAT:** Large Group

**LOCATION:** Meet outside Hyatt Regency Hotel

**ACTIVITY:** Buses load and leave promptly at 2:45 for return trip to CSUS!

**SEGMENT 31- 5:00-6:00 p.m. - DINNER SERVED**

**FORMAT:** Individuals

**LOCATION:** Residence Dining Hall

**ACTIVITY:** Dinner (not in small groups)  
**(AFTER DINNER, PROGRAM ASSISTANTS DECORATE  
RECREATION ROOM FOR DANCE)**

**SEGMENT 32- 7:30-10:00 p.m. - DANCE**

**FORMAT:** Large group

**LOCATION:** Desmond Hall Recreation Room

**ACTIVITY:** Dance (with pizza and other refreshments served at 8:00 p.m.)

**SEGMENT 33- 10:00 p.m. - PERSONAL TIME**

**FORMAT:** Individual

**LOCATION:** Desmond Residence Hall

**ACTIVITY:** Brief Staff Meeting (all staff, except Program Assistants) and  
personal time to begin packing for return trip home

***10:30 p.m. LIGHTS OUT***

**THURSDAY, AUGUST 7, 1997**

**SEGMENT 34- 7:00-8:00 a.m. - BREAKFAST SERVED**

**FORMAT:** Individual

**LOCATION:** Residence Dining Hall

**ACTIVITY:** Breakfast and packing for return home

**SEGMENT 35- 9:00-11:30 a.m. - PRE - CHECK-OUT ACTIVITIES - SMALL GROUPS**

**FORMAT:** Small Groups

**LOCATION:** Desmond Residence Hall, Meeting Rooms

**ACTIVITY:** Meetings in small groups with Co-Counselors to complete check-out tasks and forum projects. Complete all final activities, including: write letter to self; write letter to sponsor; finalize "Personal Leadership Plan"; submit a statement on one major social or policy issue or concern from each Small Group (to be presented to Policy Makers); and identify one delegate interested in serving on a statewide advisory group regarding disability issues.

**SEGMENT 36- 12:00 Noon -12:45 p.m. LUNCH SERVED**

**FORMAT:** Individual

**LOCATION:** Residence Dining Hall

**ACTIVITY:** Lunch

**SEGMENT 37- 1:00 - 2:30 p.m. - CLOSING SESSION (Session VII)  
(Starts promptly at 1:00!)  
(Introductions by Small Group #6)**

**FORMAT:** Large Group

**LOCATION:** Desmond Residence Hall, Recreation Room

**ACTIVITY:** Closing Session

***THURSDAY, AUGUST 7, 1997 (continued)***

**SEGMENT 38- 2:30 P.M. FINAL CHECK-OUT ACTIVITIES**

**FORMAT:** Delegates work with Co-Counselors in Small Groups to complete final check-out activities

**LOCATION:** Desmond Residence Hall Recreation Room (in assigned stations)

**ACTIVITY:** Complete all check-out activities, including:

- ❖ Turn in room key (and receive \$5.00 stipend)
- ❖ Turn in towel

AFTER 2:45, BEGIN TRAVEL HOME. . . .

See transportation schedule posted  
on the bulletin board.



## **SECTION II:**

# **HELPFUL IDEAS**

## **HELPFUL IDEAS: #1**

### **TOPIC: HOW TO HAVE EFFECTIVE SMALL GROUP DISCUSSIONS BASIC GUIDELINES**

When participating in small group discussions, please observe the following guidelines.

#### **PRINCIPLES TO REMEMBER:**

- All information shared is confidential.
- No individuals should feel pressured to contribute or speak, but everyone benefits when everyone participates.  
The Co-Counselors and other staff are facilitators but are not in charge of the discussions and they do not have the right answers.
- Participants will speak one at a time and not interrupt a person who is speaking.
- The group discussion is a democratic process, and all participants are equal partners.

#### **HELPFUL COMMENTS AND QUESTIONS:**

To clarify discussion points, the following comments and questions may be helpful.

- "Has anyone else had a similar experience?"
- "How did you feel when that incident occurred?"
- "What I hear you saying is..... Is that right?" -- (Facilitators rephrase in their own words the statement just made and then check to see if they are accurate.)  
"Do you know where you got that idea or why you feel that way?"

#### **OTHER POINTS:**

- When making a statement, beginning your sentence with "I" helps you take responsibility for your statement. (For example, instead of saying, "You don't need to live alone to be independent" say "I don't think you need to live alone to be independent".)
- Words are not the only means of communication. Be aware of how you communicate with your body language, facial expressions and voice tone.
- Be aware of making judgmental statements such as "You shouldn't" or absolute statements such as "You never" or "I always."
- We all interpret statements made by others and events that happen -- but we all can change how we interpret things.
- Listening is as important as speaking - both are important ways of contributing to discussions.
- A major purpose of group discussions is to learn from fellow participants and likewise teach fellow participants by sharing your experiences, ideas and feelings.

## **HELPFUL IDEAS: #2**

### **TOPIC: INCREASING OUR UNDERSTANDING OF OTHERS AND RESOLVING OUR CONFLICTS**

A major goal of the Youth Leadership Forum is to enhance our understanding of ourselves.

When we understand ourselves better, we can accomplish another major goal of the forum --improving our understanding of other people.

Conflicts and misunderstandings often occur between individuals or groups when people assume they know how other people feel, think or believe.

We hope the experiences we share during the forum will encourage you to learn more about people who may seem to be different from you.

### **A FEW THOUGHTS ABOUT RESOLVING CONFLICTS:**

You can learn to negotiate solutions to disagreements without allowing anger or blame to cloud your judgment.

We perceive things differently because we interpret everything based on our past experiences. And because each of us is unique, no one else has had our exact experiences.

Even though we are unique individuals, we all have much in common. We share basic human needs and desires.

Anger often grows out of hurt feelings. When we think our needs are being ignored, we may cut off communication or raise our voices, but such behavior is self-defeating and doesn't help us get what we want.

If you want people to understand you, it is your responsibility to assert yourself and let them know what you feel, think or need. (Even people who really care for you can't and shouldn't have to try to read your mind.)

Some actions and words mean different things to different people, depending on our backgrounds and cultures. For example, actions such as speaking very loud or making direct eye contact may please one person and upset another.

When you realize you've offended someone or hurt their feelings, you'll feel better if you apologize and acknowledge your mistake.

Be aware of how easy it is to misjudge someone by jumping to conclusions when you don't have much information. It's a better idea to try to avoid being judgmental.

## **HELPFUL IDEAS: #2 (Continued)**

Don't criticize an individual in front of others. If you feel you need to clarify something or offer a critique, speak individually with the person.

Try to analyze or evaluate the motivations behind someone's actions.

Treat others as you would like to be treated.

Compare your summaries and see where you have common ground or agreement.

During discussions, avoid defending yourself with statement such as "No I didn't". When you say this, it makes the other person's opinions seem less valuable or important.

Brainstorm possible solutions to your conflict. And don't be judgmental during brainstorming. Plan to continue working on tackling the problem and not each other.

And remind yourself that on the subject of "understanding others", each of us is a teacher and a student there's a lot to teach and learn!

## **A FEW TECHNIQUES FOR RESOLVING CONFLICTS:**

Individuals (or groups) in conflict need to explore each others' needs and concerns by taking turns describing their positions.

One person's role is to listen while the other person describes how they feel or what they think (about the issue in conflict).

The listener should record key points on a notepad, but not initially respond.

The listener then summarizes or repeats back all that's recorded -- what the other person has said and what the listener thinks the speaker may also be feeling or fearing.

The individual speaking then gives feedback about the accuracy of what the listener recorded. The individuals then reverse roles and the second person describes his or her position on the issue.

When summarizing the other's position, use clarifying statements such as "It sounds like you feel really angry with me when I make decisions without asking you. Is that right?"

The formula for effective clarifying questions is "It sounds as if you're feeling \_\_\_\_\_ because of \_\_\_\_\_. Is that correct?"

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(304) 766-4950 (Fax)  
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**STATES THAT HAVE NOT PARTICIPATED IN  
YLF TRAINING**

Alaska  
Delaware  
Hawaii  
Maine  
Mississippi  
Nebraska  
North Dakota  
Oklahoma  
South Carolina

# **National Youth Leadership Network**

# About the NYLN

Reprinted with permission from [www.nyln.org](http://www.nyln.org)

The National Youth Leadership Network (NYLN) is dedicated to advancing the next generation of disability leaders.

## The NYLN:

- Promotes leadership development, education, employment, independent living, and health and wellness among young leaders representing the diversity of race, ethnicity and disability in the United States.
- Fosters the inclusion of young leaders with disabilities into all aspects of society at national, state and local levels.
- Communicates about issues important to youth with disabilities and the policies and practices which affect their lives.

## NYLN: A History of Leadership

- 1997 - The first National Conference for Youth with Disabilities was held in Washington DC lead by the Social Security Administration. Different federal agencies were represented but a heavy emphasis was placed on Social Security and its programs.
- 1998 - A second conference was held in which a few young people who had participated in the first conference were asked to assist in the development of the conference program. The conference program still largely focused on youth fitting in the adult service system.
- 1999 - Mike Ching, attendee of the 1998 conference wrote an extensive evaluation of the 98 conferences and presented it to the federal sponsors. In this report, Mr. Ching stressed his belief that for this experience to truly be about creating leadership there needed to be youth in the lead as a council to plan, develop and implement the conferences each year. National Council on Disabilities as the lead support agency, appointed Mike to chair the first National Youth Leadership Council and to appoint members to that team. NCD supported Mike and the first official council to completely lead all the planning and implementation of the National Leadership Conference. Youth were a part of every aspect of planning and conference activities and supported the attendee's to fully participate in the experience. The council was composed of twenty members and Mike Ching, Sarah Triano and Frank Hernandez were in the lead to do most of the program planning. The rest of the YLC were responsible for mentorship and conference implementation. Sarah Triano created a small policy document with a small group of interested conference participants.

- 2000 - The lead support was transferred to the President's Committee on the Employment of People with Disabilities. Mike Ching, with the assistance of PCEPD interviewed and selected a new Chairperson for the Youth Leadership Council. Jennifer Jones was selected and with the support of PCEPD, was able to select a new team for the Youth Council. Under Jennifer's leadership, the council was then separated into a team of Council members with a select team of experienced Executive Committee members. Under the new model, the Executive team of 8 members did most of the conference planning and the YLC as a whole were responsible for mentorship of conference participants and leading conference activities. The 2000 conference session piloted the first policy agenda with all conference participants. This document was presented to members of the Presidential Task Force and the US Department of Education at the White House after the conference. The National Youth Leadership Council and all the participants of the 2000 conference began to have an important role in speaking out about policy issues that effect our community of young people with disabilities. The 2000 conference was the first year that a planning retreat was held with Executive Committee members to plan and formalize mission and goals.
- After the 2000 conference, there was no guarantee of a continued conference or YLC. In a meeting with federal sponsors, Jennifer as the 2000 chair spoke with policy makers on the importance of continuing their support for the development of youth leaders. Under the leadership of Judy Huemann, five year funding was put out in an RFP in early 2001 for potential continuation of the conference. Jennifer sought support for a new home for the group and was fortunate to find that support and guidance in the Center for Self Determination at Oregon Health Sciences University. With the partnership of the Academy of Educational Development, Lori Powers of OHSU in partnership with Jennifer, Chair of the 2000 YLC, submitted a proposal to the US Department of Education for the ongoing funds to support not only a conference but an ongoing network of youth leaders to have a voice in policy making at the federal level and to support the ongoing development of a new generation of leaders in the disability community.
- Funding was received in late spring and a transition team was formed from leaders of the YLC and past conferences to assist in the development of the National Youth Leadership Network. Jennifer stayed with the group to assist in transition and to help the group to formally elect a new chair in the fall of 2001.
- A new team of YLC members was selected in early summer 2001 and a formal training retreat is to be held in September to support the new Council to function as a planning and implementation team for the new NYLN.

# The Youth Leadership Council

The Youth Leadership Council is the governing body for the National Youth Leadership Network (NYLN). The Youth Leadership Council (YLC) is responsible for mentoring, planning and carrying out the annual conference, and other Network operations. The YLC is led by the Executive Committee (EC), YLC members serve as the first point of contact for Network participants within their local communities. Specific duties focus on mentoring and supporting local participants, and carrying out Network activities with supervision from an EC member.

## **YLC members must:**

- be between 18 and 28 years of age during the time of the conference
- have attended a past conference
- have demonstrated exceptional leadership and advocacy skills on a local, state, or national level
- have demonstrated the ability to apply what they learned at the conference to their particular leadership goals and activities

## **YLC members have a responsibility to:**

- build relationships with local contacts
- encourage new participants to join the Network
- carry out local research and public education on issues important to youth
- where possible, make a connection with their local Youth Leadership Forum (YLF)
- participate in planning and carrying out the conference. During the conference, YLC members serve primarily as mentors and instructors for participants

## **Following the conference, YLC members:**

- continue to mentor participants in their local communities
- follow-up with conference participants
- continue with any other assigned duties until new YLC members are in place

## **Current YLC Members are:**

*Names in bold are also members of the Executive Committee*

Meghan Berg

**J Paul Chase**

Todd Couture

Rocky Dertinger

**Tracee Garner**

Joe Hall

**Rebecca Hare**

Renaldo Hemphill

William Jackson

**Marissa Johnson**  
**Kristen Jones**  
Candice Jordan  
**Laurel Lawson**  
Mia Peterson  
Sabrina Shaffer  
Peter Squire  
**Goyo Stinchfield - 2001 Chairperson**  
**Betsy Valnes**

## **Our Sponsors...**

US Department of Education  
Administration on Developmental Disabilities  
Bureau of Maternal and Child Health  
Centers for Disease Control  
National Council on Disability  
President's Task force on the Employment of Adults with Disabilities  
President's Committee On Employment Of People With Disabilities (Odep)  
Social Security Administration

# NYLN

## National Youth Leadership Network

### POLICY AGENDA FOR YOUTH WITH DISABILITIES

The National Youth Leadership Network (NYLN) is a voice for young people with disabilities across the United States. We have developed this agenda for the following reasons: 1) to improve policies and services for youth with disabilities; and 2) to encourage communication among young people and policymakers about important issues.

#### Youth Leadership

- Give youth a real voice in policymaking, including meaningful positions on government boards and other policymaking groups.
- Support youth leadership conferences and other leadership activities that build young peoples' skills and encourage information sharing. Make sure that young people from diverse cultures, with different disabilities and languages, are involved in youth leadership.
- Increase opportunities for youth to mentor youth.
- Create a position on youth issues that supports the Assistant Secretary on Disability at the Department of Labor.

#### Disability and Health Services

- Agency leaders and legislators should visit places where people with disabilities get services, including sheltered workshops, nursing homes, special education classrooms, and segregated housing developments. They should talk to people with disabilities about their experiences in these places and where they want to learn, work, and live.
- Focus services and improved outcomes in low income, minority, and rural communities.
- Expand local One-Stop Centers to involve Independent Living Centers and other community agencies.
- Increase funding for translators and interpreters.
- Remove pre-existing condition exclusions from health insurance plans.

#### Education of Youth and Families

- Establish Youth Information Centers in each state that are led by young people and provide education and technical assistance, mentoring, leadership development, youth speaker bureaus, and dispute resolution, as well as gather information from youth about issues that affect them.
- Require that young people in high school receive training on policies that affect them, including the ADA, IDEA, Section 504, and Social Security. Educate high school students about their rights and responsibilities, including the importance of voting.
- Increase opportunities for youth with disabilities to graduate with a diploma, including identifying creative ways to earn school credits and developing



alternatives to assess student achievement.

- Provide youth with training on how to work with systems and use supports, such as One-Stop Centers, Vocational Rehabilitation, SSI, Medicaid, Work Incentives, and personal assistance services. Explain the benefits and limits of using public supports. Give information in understandable, informal language.
- Educate families about the importance of children and youth learning to take care of themselves and directing their lives as much as possible.

### **Technology**

- Increase funding for assistive technology.
- Encourage federal, state and local agencies, and organizations to use the Internet to communicate with youth.

### **Employment**

- Redefine eligibility for SSI/SSDI so it is not based on whether a person can work or his or her income.
- Provide more opportunities for youth to get work experience without affecting their SSI benefits.
- Create a program in the Social Security Administration that supports youth who are moving from high school to work or college.
- Increase internships, job shadowing, and volunteer programs that involve disabled youth, including more opportunities in the federal government.
- Create mentoring programs that match young people with disabilities to other people with disabilities who have jobs in their interest area.

### **Professional Training**

- Modify all teacher certification requirements to include courses on disability laws and issues, such as the ADA, IDEA, and transition planning for students in special education.
- Train professionals to support all youth in moving to meaningful careers of their choice, rather than depending on public support programs, such as SSI.
- Provide training about disability issues and consumer-direction for health care providers, service providers, and state and federal officials.
- Establish an Education Accommodation Network for professionals and mentors to get information about accommodations and support for young people with disabilities in college or vocational school.

### **Enforcement**

- Fully fund the Individuals with Disabilities Education Act (IDEA).
- Enforce IDEA, ADA, Section 504 and other laws that protect the rights of people with disabilities.
- Require that disability be listed in all equal employment opportunity notices.

### **Media**

Use radio, television, and the Internet to tell youth and families about laws and their rights. Create a public awareness campaign that communicates the message, "Everyone can work and everyone should work."

- Hold the media accountable when they give incorrect information about people with disabilities.

- Educate the public about the good things that young people do.

**For additional information about the NYLN, contact:**

Alison Turner  
NYLN Coordinator  
Center on Self-Determination  
Oregon Institute on Disability and Development  
Oregon Health & Science University  
3608 SE Powell Blvd.  
Portland, OR 97202  
503-232-9154. ext. 113  
e-mail: [turneali@ohsu.edu](mailto:turneali@ohsu.edu) [www.nyln.org](http://www.nyln.org)

The NYLN is sponsored by the US Department of Education, Office of Special Education Programs, National Council on Disability, Presidential Task Force on the Employment of Adults with Disabilities, Social Security Administration, US Department of Health and Human Services, Administration on Developmental Disabilities, Centers for Disease Control and Prevention, Maternal and Child Health Bureau, and US Department of Labor.

# **YIELD THE POWER Project**

## **YIELD THE POWER Project** **EXECUTIVE SUMMARY**

Access Living is now in its first year of the innovative and progressive two-year project, **YIELD (YOUTH for INTEGRATION through EDUCATION, LEADERSHIP and DISCOVERY) THE POWER**. The YIELD project is one of seven U.S. Department of Labor-funded demonstration grants intended to increase the participation of youth with disabilities in mainstream workforce development activities.

The YIELD project is specifically designed to create systems change and program improvements that will enable various youth programs to effectively integrate and serve youth with disabilities. The mechanisms to achieve these goals include: (1) leveraging linkages with the 53 Workforce Investment Act (WIA) funded local initiatives that provide employment services to young people throughout the city with an interest in systems change of targeted agencies' policies and program practices; and (2) ensuring that the integration of these existing programs is directed and led by young people with disabilities themselves who have been trained in Independent Living (IL) history and philosophy, demonstrate improved self-advocacy skills, and are prepared for the difficult task of integrating segregated systems.

Ensuring the meaningful integration and participation of young adults with disabilities in WIA youth programs requires more than basic compliance with technical, legal requirements related to barrier removal. As the experience with school desegregation in the second half of the twentieth-century taught, it is not enough to simply throw students from one cultural background into an unfamiliar - and often hostile - environment with students from another cultural background and expect them to adjust and succeed accordingly. Reversing the historical trend of segregation, unemployment, and ineffective transition planning for youth with disabilities requires that close attention be paid to issues of accessibility in the broadest sense of the term, which - as the literature indicates - includes cultural accessibility.

According to many of the leading researchers in the field of youth development, a strong sense of cultural identity and pride, and a connection with one's heritage and community are two of the main factors that contribute to the success of minority youth in the areas of education and employment. Unlike other minority youth, however, many young people with disabilities do not have the benefit of a generational transfer of disability history and culture through the family structure, a fact which mitigates against the formation of a positive sense of cultural identity and pride. As the political scientist, Harlan Hahn, has noted, "One of the most important problems facing the political struggle of people with disabilities is the necessity of developing a positive sense of identity."

Promoting a system-wide increase in the participation of youth with disabilities in existing youth employment-readiness programs, therefore, requires a great deal more in terms of access and cultural understanding than might be expected. Youth with

disabilities who have a well-developed sense of cultural identity and pride will be better prepared to participate in existing youth employment development programs, and enter the mainstream work force with the knowledge and skills necessary to become independent and contributing members of the community. Given the high correlation between educational/vocational success and a strong sense of cultural identity, Access Living has responded to this challenge with the creation of an extremely innovative project, the YIELD the Power project, that not only addresses the lack of cultural identification and pride among disabled youth, but also adheres to a fundamental requirement of any successful youth-change effort, the requirement that the program be *directed and led by* youth with disabilities themselves.

In collaboration with the National Council on Independent Living, the Great Lakes ADA Disability and Business Technical Assistance Center, the Chicago Public Schools (CPS), and two of the city of Chicago's departments - the Mayor's Office for People with Disabilities (MOPD) and the Mayor's Office of Workforce Development (MOWD), YIELD project staff will prepare young people with disabilities to **INTEGRATE** existing WIA youth employment-readiness programs by:

1. Providing **LEADERSHIP** and organizing training to one hundred youth with disabilities over the course of two years that includes: (a) information about the disability rights movement and the importance of cross-disability, cross-community organizing, (b) the development of leadership and organizing skills, (c) the opportunity to explore issues related to race, gender, sexuality, sexual orientation, age, class, and disability, and (d) support in gaining a more positive sense of self and disability identity;
2. Empowering YIELD project trainees to **EDUCATE** existing WIA youth programs through two youth-led Adult Education Conferences, and undertake systems change within those programs through on-going networking, advocacy, and technical assistance; and
3. Promoting **DISCOVERY** of new information through extensive research and evaluation activities that will provide: (a) input to existing youth programs on policies and best practices, (b) quantitative and qualitative feedback to the Principle Investigator to enhance data collection and program assessment/refinement efforts, and (c) an opportunity for the youth participants to "evaluate the evaluators," and learn to question the role of assessment/evaluation in their lives through extensive use of participatory action research methodology throughout the project.

The central role played in the YIELD project by the population directly impacted - youth with disabilities - is what makes this project innovative. The project design recognizes, and directly incorporates, the understanding that the key to making substantive change is getting power into the hands of the people directly affected by a problem so that they can exercise their power to solve that problem. The YIELD project is directed and led by a paid Youth Advisory Board comprised of seven disabled youth, and every member of

the project staff is a young adult with a disability under the age of 30 who grew up with their disability. The one hundred youth trainees of the YIELD project, furthermore, will have the opportunity to desegregate, integrate, and participate in existing employment-readiness programs for youth in the Chicago area, thereby gaining extensive self-advocacy skills while also increasing their interest in education, future careers, and community involvement. The trainees will enter these programs knowing what questions to ask, what information and policies to look for, and what barriers presently exist in WIA funded and other youth programs.

Ed Roberts, one of founding members of the disability civil rights movement, once said, "We will not tolerate another generation of young people with disabilities going through segregated education, segregated society, being dependent on their parents and public aid. We can make a difference in their future." Through the YIELD the Power Project, Access Living is empowering young people with disabilities to fight the continued "ghettoization" of disabled youth into segregated systems. *Youth with disabilities* in the YIELD project are the ones making a difference in their own future, the true meaning of IL philosophy and youth-led social change.

YIELD THE POWER!

# JOIN **YIELD** the Power Project!

Youth for Integration through Education,  
Leadership, and Discovery.

- Learn about the disability rights movement and how it relates to civil rights
- Develop valuable leadership and advocacy skills
- Fulfill service learning requirement for graduation
- Food & accommodations provided!

## **Who?**

People with disabilities between the ages of 14 and 21.

## **What?**

Access Living 's **Y.I.E.L.D.** the Power Project: a 16- week intensive leadership and organizing training.

## **When?**

Every Saturday for 16 weeks starting March 2nd, 2002. Four 16 week trainings will be held over the course of the next two years.

- . March 2, 2002- June 15, 2002
- . August 3, 2002- November 30, 2002
- . January 4, 2003- April 19, 2003
- . May 3, 2003- August 23, 2003

## **Where?**

Access Living of Metropolitan Chicago  
614 W. Roosevelt Rd., Chicago IL 60607

What do these people have in  
common?

To the PEOPLE!  
The Power

## **Organization**

**Not Fit.?**

**PHAT.**

fight the power...

For more information, contact  
Marketo Day  
(312) 253-7000 (voice)  
(312) 253-0332 (TTY)  
yieldinfo@accessliving.org  
or www.yieldthepower.org



# Find Out yOUR History,

## The History of Disability Civil Rights

Curtis Mayfield: paraplegic

Abraham Lincoln: Depression

CHER: LEARNING DISABILITY

Ray Charles: blind

**Helen Keller: blind, deaf**

Bill Clinton: hearing impairment

Tom Cruise: learning dis.

Lou Ferrigno: hearing impairment

Emily Dickinson: Depression

Harriet Tubman: epilepsy

Whoopi Goldberg: learning dis.

Einstein: learning dis.

*Frida Kahlo: polio*

**Mary Wells: muscular dystrophy**

Gabrielle: weak eyelid

Mohammad Ali: Parkinson's Disease

Billy Barty: short stature

Aristotle: epilepsy

FDR: polio

Sammy Davis Jr.: blind

James Earl Jones: speech impairment

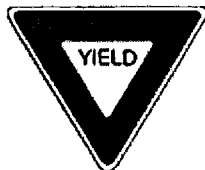
Gary Coleman: short stature

Marilyn Monroe: speech impairment

Janet Reno: Parkinson's disease

BEST COPY AVAILABLE

Applications are now being accepted for Access  
Living's  
**YIELD THE POWER Project**



**(Youth for Integration through Education, Leadership, and Discovery)**

- WHO:** Young people with disabilities between the ages of 14 and 21
- WHAT:** 16 week intensive leadership and organizing training project for young people with disabilities that includes:
- the development of leadership and organizing skills through experiential learning
  - increased knowledge of the disability rights movement and cross-disability organizing
  - the opportunity to explore disability in the context of race, gender, sexuality, sexual orientation, age, and class
  - the chance to come together with other young people with disabilities and get more involved in the disability civil rights movement
  - **FREE FOOD!!**
  - **PARTICIPATION IN THIS PROJECT FULFILLS THE SERVICE LEARNING REQUIREMENT FOR GRADUATION!!**
- WHEN:** Every Saturday for 16 weeks starting in March  
4 trainings will be held over the course of the next two years:
- **TRAINING #1:** March 2, 2002 through June 15, 2002
  - **TRAINING #2:** August 3, 2002 through November 30, 2002
  - **TRAINING #3:** January 4, 2003 through April 19, 2003
  - **TRAINING #4:** May 3, 2003 through August 23, 2003
- WHERE:** Access Living of Metropolitan Chicago, 614 West Roosevelt Road, Chicago, IL 60607

For more information, call 312-253-7000 x 186 (voice), 312-253-0332 (TTY), 312-253-7001 (fax), [yieldinfo@accessliving.org](mailto:yieldinfo@accessliving.org) (e-mail), or [www.yieldthepower.org](http://www.yieldthepower.org) (URL)



10/29/01

## **Job Posting**

### **Youth Leadership and Organizing Coordinator**

Access Living of Metropolitan Chicago, a Center for Independent Living, seeks a full-time Youth Leadership and Organizing Coordinator for its innovative and progressive two-year project, YIELD (Youth for Integration through Education, Leadership, and Discovery) THE POWER. The YIELD project is part of a two-year U.S. Department of Labor, Office of Disability and Employment Policy, innovative demonstration grant for youth with disabilities designed to increase the participation of youth with disabilities in mainstream workforce development activities.

This position involves the development and implementation of a leadership, organizing, and independent living skills training program for one hundred youth with disabilities, ages 14-21, over the course of two years. In addition to setting up the program, the Coordinator will be responsible for conducting four 16-week leadership/organizing trainings using an existing youth leadership and organizing curriculum, and replication/dissemination of the curriculum. The position requires some local and out-of-town travel, as well as working on Saturdays.

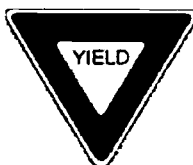
Applicants with experience working with young people, as peers or allies, is preferred. We are seeking applicants with group facilitation skills and familiarity with the disability rights movement and/or independent living movement. This position is particularly suited for individuals who are committed to youth-led social change. People with disabilities, and members of other minority communities, are highly encouraged to apply.

Access Living offers excellent medical and vacation benefits.

Interested Candidates should mail or fax a resume and cover letter to:

**Sarah Triano**  
**Youth and Education Team Leader/ YIELD The Power Project Director**  
**Access Living**  
**614 West Roosevelt Road**  
**Chicago, IL 60607**

**(312) 253-7000 (phone)**  
**(312) 253-7001 (fax)**  
**(312) 253-7002 (tty)**  
**[sarah@accessliving.org](mailto:sarah@accessliving.org)**



**THE POWER!!**



10/29/01

## **Job Posting**

### **Youth Outreach and Advocacy Coordinator**

Access Living of Metropolitan Chicago, a Center for Independent Living, seeks a full-time Youth Outreach and Advocacy Coordinator for its innovative and progressive two-year project, YIELD (Youth for Integration through Education, Leadership, and Discovery) THE POWER. The YIELD project is part of a two-year U.S. Department of Labor, Office of Disability and Employment Policy, innovative demonstration grant for youth with disabilities designed to increase the participation of youth with disabilities in mainstream workforce development activities.

This position involves enhancing the capacity of existing Work Investment Act (WIA) Title I Youth programs in Chicago to integrate and serve youth with disabilities; assisting selected youth trainees of the YIELD project to lead and coordinate these efforts; and providing support to YIELD trainees who enter and participate in these, and other, mainstream youth programs. The position requires some local and out-of-town travel, as well as working some Saturdays.

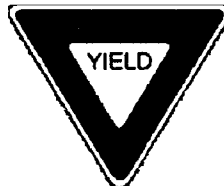
Experience working with young people (as peers or allies), knowledge of disability civil rights laws (ADA, 504, and IDEA), and familiarity with the disability rights movement and/or independent living movement is preferred. This position is particularly suited for individuals who are committed to youth-led social change. People with disabilities, and members of other minority communities, are highly encouraged to apply.

Access Living offers excellent medical and vacation benefits.

Interested Candidates should mail or fax a resume and cover letter to:

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**Access Living**  
**614 West Roosevelt Road**  
**Chicago, IL 60607**

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**(312) 253-7002 (tty)**  
**[sarah@accessliving.org](mailto:sarah@accessliving.org)**



**THE POWER!!**



10/29/01

## Job Posting

### Youth Leader/Organizer

Access Living of Metropolitan Chicago, a Center for Independent Living, seeks two youth with disabilities to serve as quarter-time Youth Leaders/Organizers for its innovative and progressive two-year project, YIELD (Youth for Integration through Education, Leadership, and Discovery) THE POWER. The YIELD project is part of a two-year U.S. Department of Labor, Office of Disability and Employment Policy, innovative demonstration grant for youth with disabilities designed to increase the participation of youth with disabilities in mainstream workforce development activities.

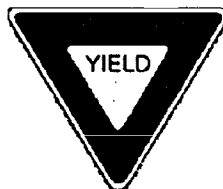
These positions involve serving as peer counselors for the participants in the YIELD project, and providing input and guidance, from a youth perspective, on all aspects of the project (particularly those related to furthering employment outcomes for youth with disabilities). The position requires some local and out-of-town travel, as well as working on Saturdays.

Young persons with disabilities who demonstrate leadership and organizing potential, and who come to the project with a diverse set of life experiences, are preferred. This position is particularly suited for youth with disabilities who would like to become more involved in the disability rights movement and in the larger movement for social justice. Experience with peer counseling and organizing is recommended, but not required. Youth with disabilities, particularly young, disabled adults from other minority communities, are highly encouraged to apply.

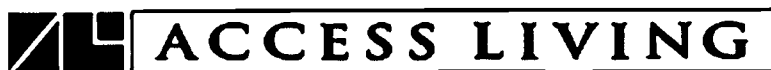
Interested candidates should mail or fax a resume and cover letter to:

**Sarah Triano**  
**Youth and Education Team Leader/ YIELD Project Director**  
**Access Living**  
**614 West Roosevelt Road**  
**Chicago, IL 60607**

**(312) 253-7000 (phone)**  
**(312) 253-7001 (fax)**  
**(312) 253-7002 (tty)**  
**sarah@accessliving.org**



**THE POWER!!!**



10/29/01

## **Job Posting**

### Youth Advisory Board

Access Living of Metropolitan Chicago, a Center for Independent Living, seeks 5-6 young adults with disabilities to serve on a Youth Advisory Board for its innovative and progressive two-year project, YIELD (Youth for Integration through Education, Leadership, and Discovery) THE POWER. The YIELD project is part of a two-year U.S. Department of Labor, Office of Disability and Employment Policy, innovative demonstration grant for youth with disabilities designed to increase the participation of youth with disabilities in mainstream workforce development activities.

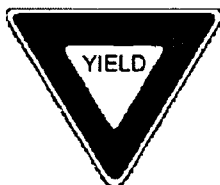
Participation on the Youth Advisory Board involves providing guidance and oversight on all YIELD-project related activities from a youth and systems change perspective. Youth Advisory Board members are required to attend quarterly meetings of the Board (approximately 2-3 hours each) and a full day retreat in December. Members of the Youth Advisory Board will be paid for their time and participation.

Young adults with disabilities (late teens/early twenties) who demonstrate leadership and organizing potential, and who come to the project with a diverse set of life experiences, are preferred. This position is particularly suited for young persons with disabilities who would like to become more involved in the disability rights movement and in the larger movement for social justice. Youth with disabilities, particularly young, disabled adults from other minority communities, are highly encouraged to apply.

Interested Candidates should mail or fax a resume and cover letter to:

**Sarah Triano**  
**Youth and Education Team Leader/ YIELD Project Director**  
**Access Living**  
**614 West Roosevelt Road**  
**Chicago, IL 60607**

**(312) 253-7000 (phone)**  
**(312) 253-7001 (fax)**  
**(312) 253-7002 (tty)**  
**[sarah@accessliving.org](mailto:sarah@accessliving.org)**



**THE POWER!!!**



## YIELD THE POWER Project

**Y**outh for  
**I**ntegration through  
**E**ducation  
**L**eadership and  
**D**iscovery

### Project Collaborators:

Access Living

Mayor's Office of Workforce  
Development

Mayor's Office for People with  
Disabilities

The Office of Specialized  
Services, Chicago Public Schools

Great Lakes ADA Disability  
Business and Technical  
Assistance Center

The National Council on  
Independent Living

The UIC RRTC on Aging with  
Developmental Disabilities

U.S. Department of Labor, Office  
of Disability Employment Policy

**Access Living of  
Metropolitan Chicago**  
**614 West Roosevelt Road,**  
**Chicago, IL 60607**  
**312-253-7000 (v), 312-253-7001 (fax),**  
**312-253-0332 (tty)**  
**yieldinfo@accessliving.org (e-mail),**  
**www.yieldthepower.org (URL)**

Dear Prospective Applicant:

Access Living of Metropolitan Chicago invites you to apply for the innovative YIELD THE POWER Project. The YIELD THE POWER Project is a **16 week leadership and organizing training program** for young people with disabilities that includes:

- the development of leadership and organizing skills through experiential learning
- increased knowledge of the disability rights movement and cross-disability organizing
- the opportunity to explore disability in the context of race, gender, sexuality, sexual orientation, age, and class
- the chance to come together with other young people with disabilities and get more involved in the disability civil rights movement
- **FREE FOOD!!**
- the opportunity to fulfill the service learning requirement for graduation

**Four 16-week leadership and organizing training sessions will be conducted throughout 2002 and 2003:**

Training	Start Date	End Date	Application Deadline
Training #1	March 2, 2002	June 15, 2002	February 11, 2002 <b>Extended to February 20, 2002</b>
Training #2	August 3, 2002	November 30, 2002	July 15, 2002
Training #3	January 4, 2003	April 19, 2003	December 16, 2002
Training #4	May 3, 2003	August 23, 2003	April 14, 2003

To apply for one of these training sessions, **please complete the attached application and submit it by the corresponding deadline noted above.** Only 25 participants will be selected for each training, so get your application in soon.

If you have any questions or concerns while filling out the application, or if you need help filling out the application, please do not hesitate to contact one of the YIELD Project staff at 312-253-7000 x 186 (voice), 312-253-0332 (tty), 312-253-7001 (fax), or send an e-mail to [yieldinfo@accessliving.org](mailto:yieldinfo@accessliving.org). We look forward to receiving your application soon.

Sarah Triano, Marketoe Day, Kristin Berg, Heather Harris, and  
Dellon Lewis  
YIELD THE POWER Project Staff



## **YIELD THE POWER Project APPLICATION FORM**

**(Youth for Integration through Education, Leadership, and Discovery)**

### **TRAINING PROGRAM:**

16 week leadership and organizing training program for young people with disabilities.

### **TRAINING DATES/APPLICATION DEADLINES:**

<b>Training</b>	<b>Start Date</b>	<b>End Date</b>	<b>Application Deadline</b>	<b>Notification Date*</b>
Training #1	March 2, 2002	June 15, 2002	February 11, 2002 <b>Extended to February 20, 2002</b>	February 25, 2002
Training #2	August 3, 2002	November 30, 2002	July 15, 2002	July 22, 2002
Training #3	January 4, 2003	April 19, 2003	December 16, 2002	December 20, 2002
Training #4	May 3, 2003	August 23, 2003	April 14, 2003	April 21, 2003

### **ELIGIBILITY REQUIREMENTS:**

**To be eligible to apply for the YIELD Project you must:**

- **Be a young person with a disability between the ages of 14 and 21.**  
We are looking for young people with all kinds of disabilities (physical, developmental, hidden, learning, psychiatric, etc).
- **Want to participate**
- **Be committed to participating in the full 16 weeks of the training.**  
In other words, you must agree to come to Access Living every Saturday for 16 weeks for approximately three and a half hours. Food and all accommodations will be provided (including gold ticket vouchers).

### **APPLICATION INSTRUCTIONS:**

To apply, fill out the information on the attached application form and mail, fax, or e-mail your completed application by the deadline to:

**YIELD THE POWER Project Selection Committee**  
**Access Living of Metropolitan Chicago**  
**614 West Roosevelt Road**  
**Chicago, IL 60607**

### **FOR MORE INFORMATION:**

**For more information, please contact the YIELD THE POWER staff at:**

- **Telephone:** 312-253-7000 x 186 (voice) or 312-253-0332 (tty)
- **Fax:** 312-253-7001
- **E-mail:** [yieldinfo@accessliving.org](mailto:yieldinfo@accessliving.org)
- **Internet:** [www.yieldthepower.org](http://www.yieldthepower.org)

\* NOTIFICATION DATE: You will be notified by the date indicated if you were selected to participate in the training.



# YIELD THE POWER Project Application Form

## Application Information

Name:

Date of  
Birth/Current Age:

Phone (voice):

Phone(TTY):

Permanent Address:

City:

State:

ZIP/ County:

Other Address (if different than above):

City:

State:

ZIP/ County:

Fax:

E-mail:

Social Security Number:

## Demographic Information

We value diversity of all kinds and we are asking these questions to ensure a diverse group of participants.

☐ Female ☐ Male ☐

Ethnicity:

Decline to State (please check  
one)

Disability:

Sexual Preference (optional):

Is English your native language?  
If not, what is your native  
language?

Religious Affiliation (optional):

Parent/Guardian's Estimated Annual Income (please check one):

☐ \$0-10,000

☐ \$10,000-\$30,000

☐ \$30,000-\$50,000

☐ \$50,000-\$70,000

☐ \$70,000-\$100,000

☐ \$Over \$100,000

## School Information

School Name:

School Address:

City:

State:

ZIP/County:

School Telephone  
Number:

Name of School Contact  
(teacher, principal, counselor):

Grade in School:

## Parent/Guardian Emergency Contact Information

Parent/Guardian Name:

Address:

City:	State:	ZIP/County:
Daytime Phone (v/tty):	Evening Phone (v/tty):	Fax or mobile (please indicate):

Are you (the parent/guardian) interested in participating in a parent group that will be held at the same time as the Youth Leadership/Organizing trainings? (please check one):

☐ Yes ☐ No ☐ Maybe (please send me more information)

## Accommodations

**What accommodations will you need to participate in the YIELD THE POWER project trainings? (please check all that apply)**

- |   |  |
|---|--|
| <input type="checkbox"/> Sign Language Interpreter  | <input type="checkbox"/> Reader  |
| <input type="checkbox"/> Assistive Listening Device   | <input type="checkbox"/> Note Taker  |
| <input type="checkbox"/> Real Time Captioning   | <input type="checkbox"/> Tape recorder to tape sessions                                |
| <input type="checkbox"/> Materials in Braille   | <input type="checkbox"/> Learning Coach  |
| <input type="checkbox"/> Materials in Large Print   | <input type="checkbox"/> No florescent lights  |
| <input type="checkbox"/> Materials in Plain English   | <input type="checkbox"/> Personal Care Assistant                                       |
| <input type="checkbox"/> Materials in a Different Language                                    | <input type="checkbox"/> A place to rest, when needed                                  |
| <input type="checkbox"/> Materials in Electronic Format (tape, disk, etc)                     | <input type="checkbox"/> Wheelchair accessible location/restroom                       |
|   | <input type="checkbox"/> No fragrances or scented products in the training environment |
| <input type="checkbox"/> Need speakers/presenters to use a microphone                         |  |
| <input type="checkbox"/> Presentation of materials in an accessible pace and organized format |  |
| <input type="checkbox"/> Dietary requirements (please specify):                               |  |

**Please clarify the information provided above, if needed (or let us know about an accommodation you may need that is not included on this list):**

## Application Questions

Please respond to the following questions in a format of your choice that is most accessible to you (for example, written essay, videotape, or audiotape). Your total responses to these questions should not exceed the space provided or five minutes of taped response.

<b>Question #1</b>	<b>Why do you want to participate in the YIELD THE POWER Project?</b>
<b>Question #2</b>	<b>How would a friend or family member describe you?</b>

Question #3	Please describe any two people who have had a positive influence on your life – people you look up to – for example, a teacher, a philosopher, a historical or national figure, someone close to you, a fictitious character, etc.
Question #4	<p>Which training session are you applying for? (please check one):</p> <p><input type="checkbox"/> Training #1 (March 2, 2002 – June 15, 2002)</p> <p><input type="checkbox"/> Training #2 (August 3, 2002 – November 30, 2002)</p> <p><input type="checkbox"/> Training #3 (January 4, 2003 – April 19, 2003)</p> <p><input type="checkbox"/> Training #4 (May 3, 2003 – August 23, 2003)</p>
Question #5	<p>If the first training session of your choice is full, would you still like to be considered for one of the other training sessions? (please check one):</p> <p><input type="checkbox"/> Yes                      <input type="checkbox"/> No</p> <p>If yes, please indicate your preference (i.e. first, second, or third):</p> <p>_____ Training #1 (March 2, 2002 – June 15, 2002)</p> <p>_____ Training #2 (August 3, 2002 – November 30, 2002)</p> <p>_____ Training #3 (January 4, 2003 – April 19, 2003)</p> <p>_____ Training #4 (May 3, 2003 – August 23, 2003)</p>
Question #6 (optional)	Is there anything else that you would like to share with the selection committee?

## Declaration of Commitment Application and Parent/Guardian

I declare that the information I have provided above is accurate and true to the best of my knowledge. By signing this form, I am indicating my willingness to participate in the YIELD THE POWER project, and my commitment to participating in all project-related activities for the full 16 weeks.

Signature of Applicant

Date

I declare that the information provided by my daughter/son is accurate and true to the best of my knowledge, and I support her/his application for the YIELD THE POWER project.

Signature of Parent/Guardian

Date

**Mail your completed application to:**  
YIELD THE POWER Project Selection Committee  
Access Living of Metropolitan Chicago  
614 West Roosevelt Road  
Chicago, IL 60607

# News Release



U.S. Department of Labor  
Office of Disability Employment Policy  
Washington, D.C.  
USDL [01-332]

For Immediate Release  
October 1, 2000  
Contact: Dina Dorich  
Phone: (202) 276-6200

## **LABOR DEPARTMENT ANNOUNCES \$11 MILLION IN GRANTS TO SUPPORT NEW FREEDOM INITIATIVE**

**WASHINGTON** -- U.S. Labor Secretary Elaine L. Chao today announced \$11.3 million in federal grants that will support the President's New Freedom Initiative goal to integrate Americans with disabilities into the workforce. These grants, which range in amount from \$1.4 million to \$50,000, will be used to develop innovative programs and technical assistance that will improve employment outcomes for adults and youth with disabilities.

"I am pleased to announce a series of grant awards that will directly support the goals of the President's New Freedom Initiative of bringing persons with disabilities into the workforce," said Chao. "The grants will ensure that all of the Department's job-related programs are fully available to people with disabilities. Helping to fully integrate Americans with disabilities into the mainstream of our economy is critically important to meeting the challenges of the 21<sup>st</sup> century economy."

Thirty-three grants have been awarded in the following five categories: Customized Employment for Adults with Disabilities, Workforce Investment Act (WIA) Disability Technical Assistance Consortia for Youth and Adults with Disabilities, Innovative Demonstration Grants for Youth with Disabilities, High School/High Tech Start-up Programs and High School/High Tech Realignment Programs.

The various grantees will be working to develop model programs or technical assistance initiatives that will enhance opportunities for people with disabilities in various DOL work-related programs, as well as to strengthen the capacity of these programs to serve people with disabilities. Successful programs will be replicated across the United States.

The grants are the first to be awarded through the Labor Department's new Office of Disability Employment Policy and will be administered by that office.

EDITOR, PLEASE NOTE: A list of grant recipients for each of the programs is attached.

###

U.S. Labor Department news releases are accessible on the Internet at [www.dol.gov](http://www.dol.gov). The information in this release will be made available in alternate format upon request (large print, Braille, audio tape or disc) from the COAST office. Please specify which news release when placing your request. Call 202-693-7773 or TTY 202-693-7755.

## High School/High Tech Start-Up Grant Awardees

A total of \$600,000 has been awarded to 12 organizations to develop demonstration High School/High Tech (HS/HT) program sites that would align the HS/HT program with the Workforce Investment Act's (WIA's) youth-related programs.

The grants, to organizations that provide youth services, will provide start-up funds for new programs modeled on the national High School/High Tech series of programs that provide young people with disabilities an opportunity to explore their interest in technology-related careers. These locally directed and supported programs serve either in-school or out-of-school youth with disabilities in a year-long program of corporate site visits, mentoring, job shadowing guest speakers, after school activities and paid summer internships. Each grant is awarded for a one-year period, with one option year, subject to the availability of funds.

Hillsborough County Public Schools 5410 North 20 <sup>th</sup> Street Tampa, FL 33610	\$50,000
Center for Independent Living of Broward, Inc. 8857 West McNab Road Tamarac, FL 33321	\$50,000
Able-Disabled Advocacy 2850 6 <sup>th</sup> Avenue San Diego, CA 92101	\$50,000
DO-IT Program University of Washington Seattle, WA 98195	\$50,000
Work and Rehabilitation Centers of Greater Cincinnati 2901 Gilbert Avenue Cincinnati, OH 45206	\$50,000
Jewish Vocational Service 77 Geary Street Suite 401 San Francisco, CA 94108	\$50,000
Job Service North Dakota 1000 E. Divide Avenue Bismarck, ND 58506	\$50,000

Cooperative Educational Services Agency #7 595 Baeten Road Green Bay, WI 54304	\$50,000
Chicago Public Schools 125 South Clark Street Chicago, IL 60603	\$50,000
Burlington School District 150 Colchester Avenue Burlington, VT 05401	\$50,000
Montana Center on Disabilities Montana State University-Billings 1500 North 30 <sup>th</sup> Street Billings, MT 59101	\$50,000
City of Anaheim 50 S. Anaheim Boulevard Anaheim, CA 92805	\$50,000



## Customized Employment Grants

More than \$4.4 million in U. S. Department of Labor grants has been awarded to seven Workforce Investment Boards across the United States for strategic planning and implementation activities designed to improve the employment and career advancement of people with disabilities.

The key goal of the grants is to build the capacity in local One-Stop Career Centers to develop and implement customized employment services to persons with disabilities. The grants provide a vehicle for the local boards to systemically review their policies and practices in service to persons with disabilities and to incorporate new and innovative practices, as appropriate. The grants are awarded for a one-year period, with four option years, subject to the availability of funds.

Recipient	Grant Amount
Metro North Regional Employment Board Riverview Business Park, 300 Commercial St., Suite 27 Malden, MA 02148	\$418,100
NAPA County 1700 Second Street, Suite 378 NAPA, CA 94559	\$749,394
Anoka County Job Training Center 1201 89 Avenue, NE, #400 Blaine, MN 55434	\$682,062
Knoxville-Knox County Community Action Committee 2247 West Avenue/PO Box 51650 Knoxville, TN 37950-1560	\$600,000
Cobb Community Service Board 361 North Marietta Pkwy Marietta, GA 30060	\$689,040
The Northern Virginia Workforce Investment Board 12011 Government Center Parkway, 5 <sup>th</sup> Floor Fairfax, VA 22035	\$594,509
San Diego Workforce Partnership, Inc. 1551 Fourth Ave., Ste. 600 San Diego, CA 92101	\$750,000

## High School/High Tech Realignment Grants

A total of \$165,000 has been awarded to five grantees to allow 11 existing High School/High Tech program sites to move into alignment with the Workforce Investment Act (WIA) youth programs. The realignment grants are to be use to develop strategies, relationships, joint funding and/or support through which High School/High Tech programs for young people with disabilities can enter into a new or stronger partnership with one or more of the Workforce Investment Act (WIA) youth-focused programs. The grants are awarded for a one-year period.

The High School/High Tech programs, which operate nationwide, are designed to provide young people with disabilities with an opportunity to explore their interest in technology-related careers. These locally directed and supported programs serve either in-school or out-of-school youth with disabilities in a year-long program of corporate site visits, mentoring, job shadowing guest speakers, after school activities and paid summer internships.

The WIA youth programs include WIA Local Workforce Investment Boards and their Youth Councils, Job Corps Centers, Youth Opportunity Grant programs, WIA formula-funded youth programs, WIA Native American programs, and WIA Migrant Worker programs.

Recipient	Grant amount
Occupational Center of Hudson County 68-70 Tuers Avenue Jersey City, NJ 07306	\$15,000
GPUAC-Workstream 1207 Chestnut Street Philadelphia, PA 19107	\$15,000
United Cerebral Palsy of Prince Georges and Montgomery Counties 3901 Woodhaven Lane Bowie, MD 20715	\$15,000
Goodwill Industries of Central Texas 300 N. Lamar Boulevard Austin, TX 78703	\$15,000
Georgia Committee on Employment of People with Disabilities, Inc. 6810 Creekview Court Columbus, GA 31904	\$105,000*

\*This total represents \$15,000 each to support the following seven programs, based in various locations, as indicated below:

- Tift County High School/High Tech – Tifton, GA
- Dodge, Bleckley, Wheeler and Telfar Counties High School/High Tech – Eastman, GA
- Dougherty County High School/High Tech – Albany, GA
- Cobb County High School/High Tech – Atlanta, GA
- Bibb County High School/High Tech – Macon, GA
- Muscogee County High School/High Tech – Columbus, GA
- Chatham County High School High Tech – Savannah, GA

## Innovative Demonstration Grants for Youth with Disabilities Awardees

Seven organizations have been awarded a nearly \$3.5 million to develop model demonstration programs that would enhance the capacity of the Department of Labor's various youth programs to serve youth with disabilities. The grants require that youth with disabilities and relevant experts work jointly to develop and implement innovative programs. Each grant is awarded for a two-year performance period.

Grant recipient	Grant amount
Pacer Center 8161 Normandale Boulevard Bloomington, MN 55437	\$492,296
Career Transition Center, Inc. 11160 Veirs Mill, Suite 510 Wheaton, MD 20902	\$493,296
Access Living, Inc. 614 W. Roosevelt Road Chicago, IL 60607	\$500,000
Hawaii Vocational Rehabilitation and Services for the Blind Department of Human Resources 601 Kamokila Boulevard, Room 515 Kapolei, HI 96707	\$499,859
Health Services Center University of Oklahoma College of Allied Health Oklahoma City, OK 73190	\$500,000
Center of Excellence in Disabilities University of Southern Mississippi 3825 Ridgewood Road, Suite 319 Jackson, MS 39211	\$500,000
Center on Self-Determination Oregon Health Sciences University 3608 SE Powell Boulevard Portland, OR 97202	\$499,816

## Technical Assistance Grant Awardees

More than \$2.6 million has been awarded to two grantees to (1) provide technical assistance support to Workforce Investment Act (WIA) One-Stop Career Centers, state and local Workforce Investment Boards and other key leaders that oversee and operate adult oriented programs in order to enable them to increase employment outcomes for people with disabilities, and (2) deliver technical assistance in order to build the capacity of the emerging and existing WIA-assisted and other youth programs to provide comprehensive services to young people with disabilities. Each grant is awarded for a one-year period, with four option years, subject to the availability of funds.

# National Disability Technical Assistance Consortium on Employment of Adults with Disabilities

The Institute for Community Inclusion  
University of Massachusetts at Boston  
100 Morrissey Boulevard  
Boston, MA 02125

\$1,200,000

## Consortia Partners

- *Law, Health Policy and Disability Center*, University of Iowa College of Law, Iowa City, IA 52242
- *Center for the Study and Advancement of Disability Policy*, 1730 K Street, NW, Suite 1212, Washington, DC 20006
- *Goodwill Industries International, Inc.*, 9200 Rockville Pike, Bethesda, MD 20814
- *National Conference of State Legislatures*, 444 North Capitol Street, NW, Suite, 515, Washington, DC 20001
- *New England Council*, 98 North Washington Street, Suite 201, Boston, MA 02114
- *National Association of Workforce Boards*, 1201 New York Avenue, NW, Suite 350, Washington, DC 20005
- *National Governors Association, Center for Best Practices*, 444 North Capitol Street, Suite 267, Washington, DC 20001
- *Institute for Community Integration*, University of Minnesota, 102 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455
- *TransCen, Inc.*, 451 Hungerford Drive, Suite 700, Rockville, MD 20850

## Workforce Development Collaborative for Youth with Disabilities

Institute for Educational Leadership

\$1,450,000

**Center for Workforce Development  
1001 Connecticut Avenue, NW, Suite 310  
Washington, DC 20036**

**Partners**

- *Academy for Educational Development*, 1825 Connecticut Avenue, NW, Washington, DC 20009
- *National Center on Secondary Education and Transition*, University of Minnesota, 6 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455
- *National Conference of State Legislatures*, 444 North Capitol Street, NW, Suite 515, Washington, DC 20001
- *National Youth Employment Coalition*, 1836 Jefferson Place, NW, Washington, DC 20036
- TransCen, Inc., 451 Hungerford Drive, Suite 700, Rockville, MD 20850
- InfoUse, 2560 Ninth Street, Suite 216, Berkeley, CA 94710
- Center for Workforce Preparation, U. S. Chamber of Commerce, 1615 H Street, NW, Washington, DC 20062
- *Goodwill Industries International, Inc.*, 9200 Rockville Pike, Bethesda, MD 20814
- National Association of Workforce Boards, 1201 New York Avenue, NW, Suite 350, Washington, DC 20005

# **Presidential Task Force on Employment of Adults with Disabilities**

## **Youth Focus Group Questionnaire**



*Draft*

### **Focus Group Guideline**

#### **I. Introduction**

- a. Name
- b. Background - work, where you live, family

#### **II. Context: Your daily lives**

- a. Let's talk about the kinds of things you do during the day. Can you describe your routine for me? What are your mornings like? Afternoons? Evenings? What's your favorite time of the day? Why?
- b. What are some of the things you like to do when you're not in school (or participating in structured activities):

(PROBE)

- Are you involved in clubs? If not, why not?
  - Are you involved in school activities?
  - What are obstacles to participating in these kinds of activities?
  - (MODERATOR: EXPLORE USE OF TECHNOLOGY/COMPUTERS/INTERNET HERE IF THESE EMERGE. IF IT DOESN'T EMERGE, IT WILL BE DISCUSSED LATER IN DISCUSSION GUIDE)
  - Etc.
- c. What do you enjoy most about work/school/your daily routine? What do you like least?
  - d. What are some of the daily obstacles you face? Which ones are easier to adapt to? Which ones are harder? Why?

#### **III. Aspirations and Opportunity**

- a. Where do you *expect* to see yourself, a few years down the road? (Probe; how far do they plan down the future?) (With younger participants, where do they see themselves when they've reached adulthood?) Does this differ from where you'd *like* to see yourself? If so, how? **(PROBE THE GAP BETWEEN WHERE THEY'D LIKE TO BE AND WHERE THEY EXPECT TO BE - PARTICULARLY ON THE FOLLOWING LEVELS:)**

(PROBE:)

- b. What are your career goals?
- c. Educational goals?
- d. Personal goals? Do you want to get married? Have kids? Play a role in your community?
- e. Economic goals? What do you hope to earn?
- f. How do you reach each of these goals? Are you on your way? If not, why not? What are the primary obstacles?
- g. If you are 'headed in the right direction', what are the major factors that helped you get to where you are? **(PROBE: PEOPLE? ORGANIZATIONS? MOTIVATORS? ETC.)** What helped motivate you?
- h. How do you think your aspirations differ from those of say, your siblings'? Why do you think they're different? **(PROBE: HOW DO EXPECTATIONS OF PARENTS DIFFER FOR THEM AND FOR THEIR SIBLINGS? IF SO' HAS IT ALWAYS BEEN THIS WAY?)**
- i. What would make it easier to reach your goals? If you had a genie in a bottle, what one or two things would you wish for to help you reach your goals?

#### IV. Influences In Your Lives

- a. Where do you go for support? Guidance?
- b. When you think about how you got to where you are.. What are some of the events in your lives that had a positive impact on decisions you made, or feelings you had about yourself and your disability? (PROBE: For example, sometimes people are motivated by opposite kinds of messages. If you're told 'you can't' then you set out to accomplish something. Or, you may have someone in your life who tells you to reach for the stars.. and you do.)
- c. Which people energized you and motivated you the most? What do/did they do and say to empower you? Are they still a part of your lives?
- d. Do you have a kind of 'mantra' or 'motto' that accompanies you? if so, what is it? What was the genesis of this motto?
- e. Do you think it's important to have a mentor? How can a mentor be of value?

- f. Do you have a mentor? Where did he/she come from? How did he/she end up in your life? (**PROBE: DO YOU RELATE BEST TO OTHERS WITH DISABILITIES? DOES IT NOT MATTER?**)
- g. in contrast to the positive forces in your life, can you describe for me the kinds of people and events and occurrences that enervate you.. that leave you feeling frustrated or unempowered?
- h. I'd like to talk about expectations that people have for you... parents, teachers, employers. Do you find that people expect too much from you...or that they don't expect enough from you? Which would you prefer - expectations that are too high or too low? How do expectations hurt you? Help you?

#### **IV. Job Preparation/opportunity**

- a. Let's talk about your how you see yourself reaching job/career goals. Are you getting the kind of training and/or the help you need to get the kind of work opportunities you're hoping for?
- b. Have you had the work experience in your younger years to make you feel comfortable in the job market? Why/why not?
- c. Do you feel equipped to go out there and find a job? A good job? A job that you like? Do you feel equipped to leave a job and find another if you're not satisfied with the work experience?
- d. If you have received training or job preparation opportunities - what have they been?
- e. Have they been useful?
- f. Which were most useful? Least useful? (**PROBE: job shadow? Visited employers? Etc.**)
- g. Where can you go for job guidance? Career guidance? What are the obstacles?
- h. If you could have more guidance in this area, describe the kind of guidance you would like? Why?

#### **V. Government and Other Sources of Assistance**

- a. How do you perceive government - national, state, local? (**PROBE: TRUST, CREDIBILITY?**) Does government play a role in your life? Does it protect you? If so, in what way? If not, how could it be protecting you?

Should the government be involved in the protection of individual rights of people with disabilities? **(EXPLORE CIVIL RIGHTS IF THE CONCEPT EMERGES)**

- b. Let's talk about government programs and services. Which ones do you find useful? Which ones are you aware of? **(PROBE: SPECIAL ED. SYSTEM; REHABILITATION SYSTEM; SOCIAL SECURITY)** Are these programs useful/helpful or do they create more difficult barriers to overcome?
- c. Would it be helpful if you knew more about government services and programs that were available to you, or do you feel you pretty much know what you need to know?
- d. Are there particular programs/pieces of legislation on the national level that have had any impact on your life?
- e. Does government protect you? If so, from what? **(IF DISCRIMINATION 15 MENTIONED, PROBE FURTHER)**
- f. Have you benefited at all from private sector efforts to help the disabled? **(PROBE RETAIL, ACCESSIBILITY, ETC.)** Do you expect more, less or the same from the private sector in terms of help and effort?
- g. Are there other sources of help and assistance that you have grown to depend on?

## **VI. Sources of Information**

- a. What kind of information needs to you have? Are they different than people without disabilities? What kind of information do you need vs. what kind of information do you want?
- b. Where do you go for particular kinds of information? In general, where do you get your general news and information from? Do you like to use the web? Listen to radio? Newspaper? TV? Whom do you trust when it comes to news and information?
- c. Where do you get the kind of information you need about the kinds of programs and services that may be of help to you?
- d. Which sources of information are credible?
- e. Which are not?
- f. Let's talk about the kinds of places you go to get information related to

your disabilities. (**PROBE COMFORT LEVEL, CREDIBILITY, AND USE OF THE FOLLOWING:**)

- Electronic (internet and computer in general) (PROBE IM
- DETAIL THE USE OF TECHNOLOGY IN THEIR LIVES.
- HOW MUCH TIME? WHAT DO THEY GET FROM IT? DO
- THEY POSSIBLY HIND BEHIND IT? IS IT VALUABLE?
- HOW COULD IT BE MORE VALUABLE?)
- Newspaper
- Television
- Periodicals/magazines Community networks
- Representative organizations

## **VII. Final Thoughts**

- a. Finally, let's say that you are a member of a US government commission that is developing policy ideas to improve the lives of people with disabilities in this country. What would you identify as the two or three areas that which the commission needs to focus its attention on to better integrate people with disabilities into the schools, the economy, the country?
- b. Do you have any other thoughts you'd like to add?

*Thank you for sharing your thoughts with us*



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**National Library of Education (NLE)**  
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